

Exploring the Ethical Decision-Making Processes of Community Care Providers

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### Abstract

While there has been a recent shift away from isolated, institutionalized living conditions, persons with Intellectual Disabilities (ID) may still experience restricted access to choice when it comes to making decisions about the basic aspects of their lives. A tension remains between protecting individuals from harm and promoting their right to independence and personal liberties. This tension creates complex questions and ethical concerns for care providers supporting persons with ID. This study explored the ethical decision-making processes of care providers and specifically, how care providers describe the balance of protecting supported individuals from harm while promoting their right to self-determination. Semi-structured interviews were conducted with six care providers employed by a local community agency that supports young and older adults with ID. Data were analysed using thematic analysis and broader themes were developed following phases of open and selective coding. Results indicated that care providers described ethical decision-making processes as frequent, complex, subjective, and uncomfortable. All participants described the importance of promoting independent decision-making among the individuals they support and assisting supported individuals to make informed decisions. Participants also reported work colleagues and supervisors as primary sources of information when resolving ethical concerns. This suggests that complex ethical decision-making processes are being taken seriously by care providers and supervising staff. The results of this study are well-positioned to be applied to the development of a training program for frontline care providing staff supporting individuals in community care settings.

**Keywords:** Intellectual Disability (ID), ethical decision-making, community care.

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## **Literature Review**

### **Human Rights Violations of Persons with Intellectual Disabilities**

The promotion and support of self-determination for persons with intellectual disabilities (ID) has become a key international focus of service organizations (Stancliffe, 2001). However, the protection and promotion of such human rights for persons with ID has not always been valued. Historically, persons with ID have experienced abuse at a higher rate than the population at large throughout history (Sobsey, 1994; Owen et al., 2008). Individuals with ID have been denied basic rights such as the right to live in a community, to be married, to have children, to receive an education, to hold a job, and to receive medical treatment (Tarulli et al., 2004).

The eugenics movement of the early 20<sup>th</sup> century emerged from the belief held by scientists that improving human existence required the elimination of any genetic predisposition to disability (Owen, Griffiths, Tarulli, & Murphy, 2009). The relationship between intelligence and morality was presented as undeniable scientific truth which led persons with ID to be condemned as menaces to society (Sobsey, 1994). It was theorized that persons with disabilities were sexually immoral criminals, and that this population of people posed such a great threat to society that they warranted removal, total control and sterilization (Owen et al., 2009). Many individuals with disabilities were relegated to live in institutions under the pretence that they would receive treatment and rehabilitation. Removal from society was seen as an imperative step to achieving social control of persons with ID (Owen et al., 2009). There are numerous historical accounts of the appalling conditions of institutions that resulted from lack of funding and overcrowding. However, there are many accounts that report deliberate cases of abuse and neglect by the very people appointed to care for the residents (Sobsey, 1994). “If the rationale of

institutional care and rehabilitation was ever viable, the reality of abuse and neglect suggests that only the social control function - the ridding society of its unwanted members - was maintained” (Sobsey, 1994, p. 128). There is no doubt that the history of persons with disabilities is riddled with discrimination, rights violations, and horrific cases of abuse and neglect.

**Balancing protection and rights promotion.** Despite the long history of abuse experienced by persons with ID, disability services value and promote experiences of choice and self-determination for persons with ID (Stancliffe, 2001). However, persons with ID may still be experiencing restricted access to choice when it comes to making decisions about the basic aspects of their lives often taken for granted by persons without disabilities. These limitations are often a result of assumptions made by professional care providers that individuals may be unable to make proper decisions or are incapable of handling certain activities (Owen et al., 2003).

A tension remains between protecting individuals from harm and promoting their right to independence, self-determination and personal liberties:

The historic pull between the protection of the individual and the protection of the community at large has, to some extent, given way to a different dichotomy: the tension between protection of the individual and the promotion of the individual’s right to self-determination. (Owen & Griffiths, 2009, p. 17)

Trying to achieve this balance of protection and rights promotion has created complicated questions for family members and care-providers, such as “should I restrict a person’s access to sugar if she is a diabetic?” (Owen & Griffiths, 2009, p. 17). Accreditation Ontario (2000) reported that “the history of services for persons with disabilities reveals many examples of less than equal treatment in relation to rights” (p.1). This may be partly due to the justification of

rights restrictions based on efforts made to protect individuals with disabilities and others from harm (Tarulli et al., 2004). These justifications are based on a discriminatory bias called ableism; the belief that persons with disabilities are inferior and lack entitlement (Tarulli et al., 2004).

**Language.** It is important to establish and define terms that will be used throughout this thesis:

Intellectual Disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behaviour, which covers a range of everyday social and practical skills. This disability originates before the age of 18. (American Association on Intellectual and Developmental Disabilities, 2010)

Despite the characteristic impairments in learning and daily life skills, the most significant challenges persons with ID face are the stigmatization, stereotyping, and discrimination by others (Canadian Association for Community Living, 2010). Intellectual Disability has been referred to as *Mental Retardation* in the past. *Mental Retardation* has recently been replaced by *Intellectual Disability* in the United States (American Association of Intellectual and Developmental Disabilities, 2010). The Canadian Association for Community Living (CACL) promotes person-first language in which individuals are defined by who they are; people, first and foremost. The terms *Developmental Disability* and *Intellectual Disability* are often used interchangeably. For the purpose of this research proposal, the term *Intellectual Disability (ID)* will be used. Language used to refer to individuals with ID is very powerful. While certain labels may have negative effects, such as stereotyping, there are some benefits in such labels. An example of such benefits includes qualifying for special assistance programs that provide financial support (Brown, 2007).

Terms such as *support worker*, *care provider*, and *personal assistant* are all frequently used when referring to individuals providing support to persons with ID (Kroger, 2009). For the purposes of this study, the term *care provider* will be used. The term *care provider* will refer to a paid staff member within a community agency that supports persons with ID.

This research project explored the ethical decision-making processes of professional care providers within community agencies. These professional care providers are often faced with difficult decisions and ethical dilemmas which they are expected to resolve. These decisions often relate to the challenging task of balancing the promotion of self-determination with the duty of care, which is an inherent challenge for those supporting individuals with ID (Owen et al. 2003). This study sought to illuminate the lived experience of care providers regarding the cognitive processes involved in working through day-to-day ethical dilemmas.

### **History of Community Care for Persons with ID**

In order to contextualize this research project in terms of its relevance to the field of community care for persons with ID, the history of the disability movement and evolution of community care will now be discussed. This history forms a backdrop to the evolution of professional services and the role undertaken by care providers in those services.

**Stages of the disability movement.** Tarulli and Sales (2009) review three phases in the recent history of the disability movement, as identified by Bersani (1996). These different stages have relatively undefined boundaries, often overlapping with one another. The first wave is identified as *Professionalism*, beginning in the mid-19<sup>th</sup> and ending in the mid-20<sup>th</sup> century. This particular period emphasized the expertise of professionals in the fields of medicine, psychology,

social work and education, and the power of these experts in determining the proper course of action for persons with ID.

The second wave of the disability movement is located in the mid-20<sup>th</sup> century, and is identified as *The Parent Movement*. The National Association for Retarded Children (NARC) in the United States was formed in 1950 and was comprised of parents and relatives. The goal of the NARC was to advocate for children with ID to enjoy educational and environmental supports in order to thrive to their fullest potential. In addition, the NARC hoped to eliminate the notion that children with disabilities should be pitied or feared. During this period of time there began to be a shift in power from professionals to parents (Tarulli & Sales, 2009). The NARC also focussed on identifying the problem as existing within society (environmental barriers) rather than in the individual child with a disability, foreshadowing what is widely known as the Social Model of Disability. Similarly, the Ontario Association of Retarded Children (OARC) was formed in 1953 by parents with children who were deemed to be ‘mentally retarded’ (Owen, 1986). The original goal of this group was to advocate for governmental funding for the schools started by OARC members which children deemed to be ‘trainably retarded’ could attend. The OARC became the OAMR, the Ontario Association for the Mentally Retarded in 1965, and evolved into an advocacy group that fought for better services for persons with disabilities (Anglin & Braaten, 1978). The OAMR is known today as Community Living Ontario.

Nationally, the Canadian Association for Retarded Children (CARC) was formed in 1958, which evolved into the Canadian Association for the Mentally Retarded (CAMR) in the 1960’s (Anglin & Braaten, 1978). The CAMR is now known as the Canadian Association for Community Living and “is a national federation of over 400 local associations and 13

provincial/territorial associations for Community Living” (CACL, 2010). The shift in names of the Association reflects a significant change in the conceptualization of persons with disabilities. As the Community Living movement grew and gained momentum, opportunities for persons with disabilities to participate in society in meaningful ways became more available.

Bersani (1996) identifies the third wave as the *Self-advocacy movement* (as cited in Tarulli & Sales, 2009). This period of time is associated by an emphasis on self-determination, choice-making, self-efficacy and autonomy. In general, this wave is marked by the increase in opportunities for self-determination. Around the middle to late 20<sup>th</sup> century, there was a powerful shift toward deinstitutionalization and the beginning of the Community Living movement, as persons with disabilities began being included in everyday life (Owen et al., 2009). Self-advocacy groups, such as People First, emerged locally and globally during this period of time, establishing platforms for persons with disabilities to promote human rights and voice concerns about rights issues (Tarulli et al., 2004). People First of Canada is a self-advocacy organization founded by persons who felt that they were not considered people first and foremost. These people have been labelled “mentally handicapped, developmentally disabled, cognitively challenged, and intellectually disabled” (<http://www.peoplefirstofcanada.ca>). People First is focussed on promoting human rights, as well as citizenship, accommodations, and language rights for persons who have been labelled.

**Person-centered planning.** The term person-centered planning emerged in 1985 though the formation of the concept began in 1979 (O’Brien & O’Brien, 2002). Person-centered planning (PCP) “is a process which takes into account the unique circumstances of the individual in both the determination and implementation of a service plan” (Tarulli & Sales, 2009, p. 112).

This PCP framework is important to acknowledge and understand because many community agencies supporting individuals with ID have adopted its principles. Wehmeyer (1998) reflects on the PCP process as it pertains to decision-making processes: “The person-centered future planning procedures implemented in the last decade have shown that people with significant disabilities can be involved in the decision-making process, including making decisions about their own lives (Mount, 1994; Turnbull et al., 1996)” (Wehmeyer, 1998, p. 14).

**Importance of philosophical foundation.** Within the field of community care services for persons with ID it is important to note the beliefs, attitudes, goals and values that make up the agency’s culture. Some community care organizations grew from parent advocacy organizations. For example, Community Living Ontario was founded out of the personal investment of parents who tirelessly advocated for the development of services for children deemed mentally retarded. While advocacy and service provision are not necessarily antithetical, these functions have a different ethos that will ultimately shape the culture and role of the agency. Such organizational history and philosophical foundation have a strong influence on the role the agency grows to play in the field. An example of this struggle between advocacy and service delivery is demonstrated by Anglin and Braaten (1978) in their account of the history of the Ontario Association for the Mentally Retarded (OAMR). After intensive research and investigation the OAMR executive committee and staff prepared and presented its Position Paper on the Future Role of the Association to the OAMR Board members. This was referred to as the Role Study. One of the main points included in the report stated that the OAMR was experiencing a role conflict based on the gap between its stated goal of promoting inclusion and the actual goal of raising funds for service delivery that guided the organization’s functioning:



The stated goal in a 1973 report of the Committee on Philosophy and Priorities was ‘that retarded people share in all elements of living in the community and have the opportunity to participate effectively to the extent each person is able.’ But its actual goal is to seek more funding to expand association-operated services. (Anglin & Braaten, 1978, p. 72)

Ultimately, the Role Study was resolved and it was accepted that “OAMR will actively pursue alternative mechanisms for the provision of services through another agency or agencies, but until this is available, the associations will continue to provide services” (Anglin & Braaten, 1978, p. 80). It is clear that in order for the OAMR to establish its primary goals, the issues of function had to be addressed directly. This issue becomes critical when considering how the intention and purpose of the agency may impact the ethical decision-making processes of its employees who are working as community care providers. Depending on whether individual care providers align themselves with an advocacy function or with a service provision function, their ethical decision-making processes will likely be impacted.

The development of human rights legislation will now be reviewed in order to clarify the evolution of influential human rights treaties to the formation of self advocacy groups and a disability-specific convention on human rights.

### **Development of Rights Legislation**

In Canada the institutionalized protection of human rights is secured through documents such as The Canadian Human Rights Act (1978), The Canadian Charter of Rights and Freedoms (1982), and provincial Human Rights Codes (Tarulli et al., 2004). While rights legislation has been put in place to protect individuals with ID from experiencing rights violations, infringement of these rights remains a current problem. Examples of such rights infringements include

restricted access to medical care, education and rehabilitation; economic security; living with family members or other preferred situations; and protection from abuse or exploitation (Griffiths et al., 2003). Within services for persons with ID, detainment and restraint are commonly used as methods of control. Such arbitrary physical detainment and restraint are against the law (Griffiths et al., 2003).

Canada's Charter of Rights and Freedoms (1982) states in Article 15 that every person has the right to the equal protection and equal benefit of the law without discrimination, in particular without discrimination based on mental or physical disability. "Human rights for persons with disabilities, sometimes referred to as disability rights, are not separate from the rights guaranteed through international human rights treaties. People with disabilities are people with the same rights as all others" (Rioux, Lindqvist, & Carbert, 2007, p. 60). In 1985, Canada was the first nation to declare within its constitution the right to equal protection and benefit of the law to persons with disabilities (Owen et al., 2009). The declaration of rights within the Canadian Charter solidified that the law was indisputable and that these rights should be inherently accessible to persons with disabilities, and not something to be earned (Tarulli et al., 2004).

Recent international efforts to further promote and protect human rights of persons with disabilities are seen in the development of The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which was adopted by the General Assembly in 2006 and opened for signature in March 2007 (Owen et al., 2009). Anna MacQuarrie, policy and program director of The Canadian Association of Community Living (CACL), explained that this groundbreaking rights treaty articulates what existing human rights mean in a disability context (A.

MacQuarrie, personal communications, April 21, 2010). The UNCRPD, which was negotiated faster than any previous convention, was ratified by Canada on March 11, 2010. By ratifying the UNCRPD, Canada has committed to report to the Committee on the Rights of Persons with Disabilities every three years. As part of this process, the Committee will challenge the Canadian government to enact change in areas of need and concern. The Convention provides a framework for change as well as a tool for advocacy and a vehicle to discuss rights issues for persons with disabilities (A. MacQuarrie, personal communication, April 21, 2010). There are eight principles underlying this Convention:

Respect for inherent dignity and individual autonomy including the freedom to make one's own choices; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality and opportunity; accessibility; equality between men and women; respect for the evolving capacities of children with disabilities, and respect for the right of children with disabilities to preserve their identities.

(<http://www.un.org/disabilities/default.asp?id=259>)

The ratification of this document is worth celebration even though the most difficult work to implement the Convention has just begun. While this document represents significant movement towards rights protection on an international level, the impact of the UNCRPD will be limited until structures are established to sanction these rights in a concrete way (Owen et al., 2009). Despite the long history of discrimination and rights violations, persons with ID are increasingly being considered true citizens with access to equal rights (Rioux, Lindqvist, & Carbert, 2007).

### **Relating Rights and Ethics**

Ethical standards and codes of practice in the human services field have strong linkages to the ethos foundational to human rights. For example, the ethical principle of duty to care is reliant upon the cared-for individuals' human rights to be upheld and respected. Similarly, in psychology, the ethical principle of non-maleficence (do no harm), is dependent upon the professional acting in the clients' best interest. Ethical principles rely on the support and protection of human rights. Blau & Moncada (2009) refer to ethical responsibilities as being essential to upholding the rights of all people:

In order to realize equality of rights, there must be universal recognition that all people have *moral rights* to satisfy their basic human needs, such as for housing and food, and all people have *ethical responsibilities* to recognize these moral rights. (p. 65)

Human rights are relevant and one might even argue, foundational to the ethical standards and codes of practice in the human services field. In addition, care providers supporting persons with ID play a critical role in putting human rights and ethical principles into action.

### **Ethical Standards in Human Services**

Currently, there is no single, widely accepted code of ethics to guide professional staff working in community services for persons with ID (Owen, Sales, Griffiths & Richards, 2001). The focus of the present study is on how care providers who have been trained in human rights operate on a daily basis in the absence of a generally adopted code of professional ethics. Within the broader human service fields of social work and psychology, ethical codes and standards of practice are clearly outlined and broadly adopted. Such codes provide guidance for professionals

when faced with ethical conflicts and dilemmas. A review of ethical standards in the context of human services will outline examples of such codes of conduct.

**Ethical standards in social work and psychology.** The Code of Ethics of the Canadian Association of Social Workers (CASW) recognizes the complex nature of ethical decision-making, in which informed judgements are often made (CASW, 2005). When faced with ethical conflict, it is assumed that social workers will make a concerted effort to settle the conflict in a way that is consistent with the values outlined in the Code of Ethics. The 2005 CASW Code of Ethics draws from sections of the National Association of Social Workers (NASW) Code of Ethics (1999) in addition to the Code of Ethics of the Australian Association of Social Workers (AASW, 1999). This speaks to the universal nature of ethical codes within the field of social work. The CASW (2005) and NASW Code of Ethics (1999) provide weighted lists of principles to be used to assist social workers in ethical decision-making when faced with conflicting principles (see Appendices H and I). Neither the CASW nor the NASW Codes of Ethics prescribe universal rules of conduct for all situations, but provide guidelines for the steps to take when resolving ethical issues.

The Canadian Code of Ethics for Psychologists is clearly outlined by the Canadian Psychological Association (CPA). “The *Code* is intended to guide psychologists in their everyday conduct, thinking, and planning, and in the resolution of ethical dilemmas; that is, it advocates the practice of both proactive and reactive ethics” (CPA, 2000, p. 3). Within the Code of Ethics, the four central principles to be considered and practiced in ethical decision-making processes are outlined (see Appendix J). It is important to note that due to the likelihood of ethical principles coming into conflict with one another, they are ordered according to

importance (CPA, 2000). The CPA also outlines a set of guidelines for psychologists to be used when faced with ethical decision-making processes. The American Psychological Association (APA, 2010) outlines similar ethical principles and standards to those of the CPA (see Appendix K). The principles are aspirational in nature, meaning that while they should be considered during ethical decision-making, they are not enforceable rules. Conversely, the ethical standards outline specific rules for conduct. Psychologists and social workers are guided by common threads of integrity (in relationship and in professional practice) and respect for dignity and worth of persons (APA, 2010; CASW, 2005; CPA, 2000; NASW, 1999)

**Ethical standards in community care.** As previously stated, there is no single, widely accepted code of ethics to guide professional staff working in community service for persons with ID (Owen, Sales, Griffiths, & Richards, 2001). Various federal and provincial organizations allude to guiding ethical principles, but there is no single set of ethical guidelines for care providers to refer to in times of uncertainty. The Canadian Association for Community Living (CACL) has established guiding principles on which organizational policies and procedures are based (CACL, 2010). However, the CACL focuses primarily on broader policy and advocacy, and less on service provision and frontline staff. The United States has a national network that supports community care providers called the National Alliance for Direct Support Professionals. “The National Alliance for Direct Support Professionals (NADSP) is a membership body of organizations and individuals who share a commitment to helping people who receive community human services to live self-determined lives” ([www.nadsp.org/main/](http://www.nadsp.org/main/)). The NADSP Code of Ethics has similar underpinnings to ethical codes guiding social workers and psychologists, including principles of integrity and respect for dignity (see Appendix L).

However, the Code of Ethics outlined by the NADSP focuses on the nature of direct support relationships. Therefore, principles such as person-centered supports that are specific to the care responsibilities inherent in the job of a direct support professional are outlined (see Appendix L)

The recently launched Canadian Association for Direct Support Professionals (CADSP) aims to provide opportunities for professional development of direct support professionals (DSP) through education and leadership initiatives. While there are signs that the CADSP will be adopting the NADSP Code of Ethics, the status on this collaboration is unclear at the present time. At the time of writing the organization's website was inactive and contact with the NADSP indicated that negotiations between the organizations were inactive (J. Macbeth, personal communication, August 5, 2011).

The fact that there is no single accepted code of ethics guiding care providers in community service is problematic. While the majority of care providers working in community care will never commit serious ethical violations, there are some who may unknowingly enter into inappropriate relationships (Owen et al., 2001).

**The nature of support staff-individual relationships.** Care providers are often left to their own devices to establish the relationship between themselves and the persons they support. In their study that explored the perceptions of appropriate boundaries held by care providers and supported individuals with ID, Owen, Griffiths, Feldman, Sales and Richards (2000) examined important issues relating to the inherently intimate care-providing relationships. This study was conducted in order to explore the nature of boundaries in care provision and the relatively ambiguous role of care providers within residential services. Results of the study indicated that many individuals receiving support deemed hugs, touches on the leg and, for fewer individuals,

even kisses from care providers to be acceptable behaviour (Owen et al., 2000). These authors suggested that the existence of a code of ethics could promote a culture of heightened awareness of rights infringements by care providers while also demonstrating more diligent monitoring of these professional relationships (Owen et al., 2001). While certain professionals in the human services field are guided by ethical codes of conduct related to their individual professions, community care providers as a group are not.

To further conceptualize how care providers resolve ethical dilemmas or make ethical decisions, it is important to examine how professionals in other fields of service engage in ethical decision-making. Examples of ethical decision-making from within social work and psychology will first be reviewed. This information will be helpful in understanding ethical decision-making in community services for persons with ID, where there is limited research to draw from.

### **Ethical Decision-Making in Human Services**

The Australian Association of Social Workers defines ethics in the following way: “A system of beliefs held about what constitutes moral judgment and right conduct. Ethics are moral principles adopted by a culture, group, profession or an individual to provide rules for ethical conduct” (AASW, 1999). Ethical dilemmas exist when a choice is to be made from two equally favourable or unfavourable alternatives (O’Rourke, 2002). “When there is no clear choice, the result is ethical dissonance; feelings of discomfort, anger, frustration, and helplessness; and job dissatisfaction” (O’Rourke, 2002, p. 329). Ethical judgments are very close to personal and professional attitudes and thus, evaluation of personal values is critical in order to reflect on how these values influence ethical decisions (O’Rourke, 2002).



In publications on ethics and on intellectual and developmental disabilities, it is quite common to encounter ethical problems posed in terms of a health care provider's conflicting duties between respecting the choice of the patient or of the substitute decision-maker, on the one hand, and avoiding a preventable harm to the patient, on the other. (Heng & Sullivan, 2007, p. 620)

**Judgment-based practice versus evidence-based practice.** Polkinghorne (2004) addresses the controversy regarding the determinants of care practice of professionals in care-related fields. Specifically, this debate is centered on whether practices of care should be evidence-based or judgment-based. Polkinghorne clearly argues the need for judgment-based practice and bases this argument in the fact that practice within care professions requires a non-formulaic and context-specific judgment: "...successful practice in situations where practitioners engage others in direct face-to-face interaction requires a practice model that emphasizes the situated judgment of practitioners" (Polkinghorne, 2004, pp. 1-2).

**Phronesis.** Polkinghorne (2004) applies the Aristotelian concept of phronesis to the argument for a judgment-based practice. Phronesis "...emphasises deliberation and moral action" (Flaming, 2001, p. 251) and "comprises experience, wisdom and an ethical sense of what is right in a particular situation" (Frank, 2006, p. 253). As it pertains to practice in the human services, phronesis requires careful consideration of the context in which a situation is occurring prior to action (Flaming, 2001). Thus, this concept of phronesis relates to the context-dependent and subjective circumstances inherent in care providers' jobs of supporting individuals with ID.

Frank (2006) describes phronesis as the "wisdom to recognize what counts as moving forward, for the specific person being cared for" (p. 254). Thus, phronesis is concerned with the

quality of life of the individual receiving care. Phronesis also involves practitioners constantly reflecting and monitoring his/her practice. Similar to Polkinghorne's argument for a judgment-based practice, Flaming (2001) argues that by automatically accepting research-based practice as the superior model of practice within the human services, it devalues other legitimate forms of knowledge (e.g. intuitive or ethical knowledge). While this topic is generally discussed in relation to medicine and clinical practice in nursing, it has relevance for all human services in which the practice of care is enacted, including the ethical practice of community care professionals.

**Ethical dilemmas and decision-making in social work.** "Ethical decision-making is the process of critical reflection, evaluation and judgment through which a practitioner resolves ethical issues, problems and dilemmas" (AASW, 2010). Furman (2003) explored ethical dilemmas social workers face when dealing with Managed Mental Health Care Organizations (MMHO). Ethical dilemmas often arise due to value discrepancies faced by social workers who promote self-determination when they work in MMHO settings in which self-determination is not promoted or valued. The NASW's Code of Ethics recognizes self-determination as one of social workers' ethical responsibilities to clients. Furman recognizes the significance of addressing these ethical concerns and discusses ethical theory in social work, ethics of care and biomedical ethics as frameworks to help social workers to navigate value and ethical dilemmas. This study highlights the prevalence of ethical concerns and dilemmas involved in care services for persons who are vulnerable. However, the study does not indicate the thought processes involved or actions taken by social workers to resolve these ethical dilemmas.

McAuliffe and Sudbery (2005) investigated support-seeking and consultation behaviours of social workers when faced with an ethical dilemma. Such dilemmas are defined as situations in which there are two undesirable alternatives, and no one right answer is clear. Thirty Australian social workers were interviewed and asked how they managed serious ethical situations. Included in the interviews were questions about advice-seeking behaviour when faced with ethically uncertain situations. The main research questions included: Who do you seek advice or support from about the issue in question? Results showed that in regards to the ethical conflict reported, most social workers discussed the ethical dilemma with colleagues, with a smaller percentage discussing the issue with friends and family members. Support from an internal supervisor within the organization was only received by less than half of the participants due to practical constraints like availability and difficulty in supervisory relations (McAuliffe & Sudbery, 2005). This study supports the need for further investigation of processes involving the reconciliation of ethical dilemmas and ethical decision-making, and consequent support-seeking behaviour.

**Ethical dilemmas and decision-making in psychology.** In their literature review of ethical decision-making models, Cottone and Claus (2000) make reference to several studies that investigate the ethical decision-making processes of psychologists. According to Garfat and Ricks (1995) "...ethics is no longer about determining 'right answers,' but whether and how the counsellor decides what action to take: 'Ultimately ethical practice is moderated through and driven by the self as opposed to being driven by external variables'" (as cited in Cottone & Claus, 2000, p. 281). Smith, McGuire, Abbott and Blau (1991) explored the rationales used by mental health care professionals to resolve ethical conflicts in their jobs. The results of 102

questionnaires completed by clinical and counselling psychologists suggest that professionals tend to refer to formal codes of conduct when determining what the ethically preferred action should be. However, personal factors and values are considered when determining what they would actually do when responding to an ethical conflict.

Corey, Corey and Callahan (1998) commented on the relatively subjective nature of ethical conflicts, and the ways professionals respond to them: “Because ethical codes cannot be applied in a rote manner, practitioners are more likely to respond to a dilemma based on their personal values and practical considerations” (as cited in Cottone & Claus, 2000, p. 279). While ethical codes provide a solid set of objective principles and rules for conduct, resolving ethical dilemmas seems to have a subjective and personal component.

**Ethical decision-making in services for persons with ID.** “The field of developmental disabilities is fraught with ethical issues relating to power relationships between care providers and consumers” (Friedman, Helm & Marrone, 1999, p. 349). Ethical issues in the context of power relations such as a care provider and care recipient relationship, are further complicated. Wilson, Clegg and Hardy (2008) conducted nine interviews with professionals from within Intellectual Disability services including nurses, psychologists, rehabilitation specialists and a psychiatrist. The goal of the study was to understand how decision-making occurs within the context of ethical decisions and/or dilemmas. This was done by analysing participants’ descriptions of events in which they experienced an ethical issue within their work. Results of this study show that most participants revealed pressures to develop definitive solutions to ethical dilemmas. In addition, compassion and understanding regarding the persons with ID were of primary concern, and external guidelines were seen as less important than considering the

relationship with the person for whom they provided support. Intellectual Disability Service professionals expressed feelings of fear and anxiety when faced with ethical issues (Wilson, Clegg & Hardy, 2008). The researchers concluded by asserting that care professionals need to feel supported and reassured that “it is rarely possible to find definitive answers to ethical problems presented by people with ID” (p. 617). In addition, feelings of vulnerability and fear that are evoked by ethical dilemmas need to be addressed as discussion topics for all staff. These findings highlight the complex nature of ethical decision-making and support the need for further investigation into this issue.

Vallenga, Grypdonch, Tan, Lendemeijer, and Boon (2006) conducted an investigation of the process of risk-evaluation and subsequent decision-making in care of people with both epilepsy and ID. The study applied the methodology of focussed interviews with 15 clients and their corresponding caregiver and care-manager/nurse. Results of the study showed that the factors identified as influencing the decision-making process included level of client’s seizure activity, protective measures, other disabilities present, characteristics of the client, and other factors involving nurses and the institution. More specifically, “communicative skills of staff members, their attitudes towards care-giving, and the resources available for ensuring safety all influenced the decision-making process” (Vallenga et al., 2006, p. 608). Ethical considerations within the decision-making process were understood to be implicit in the factors identified and rarely acknowledged in concrete ways. Consensual decision-making was strongly encouraged by the policy of the epilepsy centre. Care-managers considered it to be part of their job responsibility to strive for this level of consensus (Vallenga et al., 2006). This study provides an

interesting overview of the complex factors that can influence the decision-making processes surrounding care of persons with epilepsy and ID.

Holloway (2004) explored the issue of ethical dilemmas in community living disabilities nursing. The research question guiding the study was: What sources of support help nurses resolve ethical dilemmas that result from choices made by persons with learning disabilities? The study used questionnaires to assess the types of support nurses seek to resolve ethical dilemmas. Holloway concluded that the most helpful sources of support for resolving ethical dilemmas included talking to colleagues, and the least helpful source of support was policies and procedures.

**Ethical decision-making by community care providers.** “As with many ethical dilemmas, there are no easy answers and achieving clarity for individuals who use services for persons with intellectual disabilities and their care providers is a difficult process” (Owen et al., 2003, p. 44). For care providers in the field of community services, promoting and respecting rights while upholding responsibilities to care for and protect individuals with disabilities is a delicate balance (Owen et al., 2003). The complex nature of decision-making and achieving a balance of rights promotion and protection is touched upon within the literature.

Bannerman, Sheldon, Sherman, and Harchik (1990) examined the complex nature of trying to balance the right to habilitation and the right to choice in the lives of individuals with developmental disabilities in care facilities (i.e. residential homes). Brigham (1979) defines choice as “the opportunity to make an uncoerced selection from two or more alternative events, consequences, or responses” (as cited in Bannerman et al., 1990, p. 80). Choices made by a care provider may be thought to be in the best interest of the individual and thought to promote

habilitation; however, the choices may not reflect the individual's preference. The reasons why choice is often denied to individuals within community care settings are outlined by Bannerman et al. (1990), and include: individuals are given little or no input into decisions regarding their treatment goals; no regard is shown by residential care providers for client's preferences or past learning; choice-making is not taught to persons receiving support as a skill; and opportunities for choice are not given.

While Bannerman et al. (1990) did not address the problem of personal liberty violations, ways in which the right to habilitation and the right to choice can be more effectively balanced were suggested. One example of how this balance can be achieved is for service providers to work on independent living skills that are preferred by the individual being supported. Similarly, input into decisions regarding the skills to be learned and methods of learning, should also be based on the individual being supported. Bannerman et al. suggested that the ability to make choices is often overlooked, so teaching choice-making behaviour is also important.

Not only do people strive for freedom in a broad sense, they also enjoy making simple choices, such as whether to engage in unproductive, though harmless, activities like watching sitcoms on television, eating too many doughnuts, taking the afternoon off from work, or taking a nap before dinner. These choices are cherished by most people, including those with developmental disabilities. (Bannerman et al., 1990, p. 80-81)

It is unfortunate that this issue of choice-making is still one of contention in contemporary community services for persons with ID. While Bannerman et al. leave the issue of ethical decision-making processes relatively unaddressed, researchers are beginning to explore this issue.

Dunn, Clare, and Holland (2009) conducted interviews with 21 support workers in residential homes for adults with ID in order to assess the substitute decision-making performed by the support workers on behalf of the individuals they supported. Observations of everyday care practices were also made in order to attain a holistic understanding of the care practices and decision-making processes:

Making substitute decisions on behalf of adults lacking capacity gives rise to a number of salient ethical questions: for example, who is permitted to make a substitute decision? On what basis should the substitute decision be made? Who should play a part in the substitute decision-making process? (Dunn, Clare, & Holland, 2009, p. 145)

The present study seeks to explore the ethical decision-making process of care providers, which differs from substitute decision-making process in which the individual being supported is deemed to have no ability to make decisions for him or herself.

Dunn, Clare, and Holland (2009) found that support workers made substitute decisions based on several factors including the personal routines that characterize the support workers' daily lives, as well as the desire to expose residents to new ways of living. It was clear that support workers often drew on decisions made in their own lives in order to conceptualize substitute decisions they made on behalf of individuals they supported. Support workers interpreted decision-making as a moral issue and did not consider the Code of Practice outlined in the Mental Capacity Act (MCA). The MCA aims to regulate substitute decision-making relating to the welfare of adults who lack the ability to make independent decisions about their lives. It was clear that this legal framework was not considered when it came to substitute decision-making processes (Dunn, Clare, & Holland, 2009).



Jenkinson, Copeland, Drivas, Scoon, and Yap (1992) discussed aspects of care providers' job responsibilities that make it more convenient for care providers to make decisions on behalf of the individuals they support. Access to resources, staff-client ratios, organizational structure and demanding workloads are reported as factors that interfere with care provider decision-making regarding supported individuals. Jenkinson et al. (1992) also reported that staff experience conflict as they try to balance their responsibilities to provide a safe environment for the persons they support while also encouraging autonomy and independence. These studies provide a starting point for further exploration of the ethical decision-making processes of community care providers.

### **Towards a Rights-based Service Approach**

Within the literature regarding human rights for persons with ID, a lack of studies seeking to investigate system-wide rights restrictions was identified. In response to this gap in the literature, a review of human rights restrictions within an Association for Community Living commenced. Initiated by the Executive Director of Community Living Welland Pelham, this project aimed to develop system-wide change in order to increase empowerment and goal setting for persons with ID and staff members working within community care agencies (Griffiths et al., 2003). The process began in 2001 with the identification of perceived rights restrictions. A survey package was developed by the agency and consisted of questionnaires for individuals being supported, the primary support staff, and all other support staff in residential settings. Items on the surveys were based on literature regarding rights issues relevant to the general population, as well as rights that are specific to persons with disabilities. All agency staff working in residential support as well as the individuals receiving support were invited to

complete the survey. The results of the surveys helped to illuminate the level of rights awareness among individuals receiving and providing service prior to the introduction of a system-wide rights training initiative. The type and number of rights restrictions identified by the individuals receiving agency support and the agency staff members were significantly different from one another, which seemed to indicate a wide-ranging perception of rights issues within community care (Griffiths et al., 2003). Following the survey analysis, Community Living Welland Pelham made large scale changes including the development of a Human Rights Commission, now known as a Human Rights Facilitation Committee, established to review rights restrictions. A system-wide rights training program, The 3Rs: Rights, Respect, Responsibility Training Program, was developed for individuals receiving service support, staff members, managers, and members of the Association's board of directors (Griffiths et al., 2003). Movement towards a rights-based service philosophy is exemplified by the 3Rs Project Training Programs that continue to be developed and applied in community agencies in Ontario and around the world (B. Vyrostko, personal communications, April 22, 2010).

It is evident that there has been recent and increased concern for the well-being and treatment of persons with ID. The 3Rs Project recognizes the importance of rights actualization for individuals with ID by providing rights training not only for community care providers, but also for the recipients of services themselves. However, rights restrictions may still be occurring within systems of care. For example, for individuals with ID, access to choice is still limited with respect to everyday aspects of life often taken for granted by the population at large. Ableism is still experienced by many individuals with ID, as care providers may assume that individuals cannot make their own decisions or take part in certain activities (Griffiths et al., 2003).

**Duty of care and the right to self-determination.** For care providers supporting persons with ID, there is a fine line between respecting the rights of those requiring support, and exercising the responsibility to protect people who may be deemed vulnerable. Thus, balancing duty of care and the promotion of self-determination is a complex issue faced by care providers.

It has been a commonly held belief that individuals with significant disabilities lack the capacity for self-determination (Wehmeyer, 1998). This is claimed to have resulted from the misinterpretation of the concept of self-determination as meaning independent performance; absolute control; always successful behaviour; self-reliance; and self-sufficiency or a set of skills (Wehmeyer, 1998). In addition, certain programs and service delivery models within the disability service sector are often misconstrued as “doing self-determination” (Wehmeyer, 1998, p. 12). Despite their good intentions, Wehmeyer (1998) claims that these programs fail to acknowledge that self-determination is about enabling people to take control over their lives and destinies. The ability to complete a particular task is not as significant as having control of the task outcome. For example, an individual is self-determined if they maintain control over decision-making processes and have optimal involvement in these processes (Wehmeyer, 1998). Self-determination has also been defined as “...the ability of a person to consider options and make appropriate choices regarding residential life, work, and leisure time” (Schloss, Alper, & Jayne, 1993, p. 215).

Related to this concept of self-determination is Perske’s (1972) concept of ‘dignity of risk.’ Perske explains that it is common for notions of protection and care to be elicited when people think about and/or interact with persons with disabilities. “...Such overprotection endangers the retarded person’s human dignity and tends to keep him from experiencing the

normal taking of risks in life which is necessary for human growth and development” (Perske, 1972, p. 2). According to Perske (1972), to deny persons with disabilities experiences of risk is harmful to their development. Schloss, Alper, and Jayne (1993) take this notion further, stating that not only is it harmful to the development of persons with disabilities, but it infringes on their human dignity:

People without disabilities, Perske noted, are faced with many decisions that involve some degree of physical or emotional risk. To deny the right to make choices in an effort to protect the person with disabilities from risk, he argued, is to diminish their human dignity. (p. 216)

‘Dignity of risk’ is central to the issue of balancing duty of care with the promotion of the right to self-determination. With such a fine line between these two care responsibilities, the decision-making processes of care providers are inevitably complicated (Owen et al., 2003).

### **Personal Standpoint**

**Social location.** The present research project arose out of my personal experiences as a care provider for young adults with ID. As a Community Living employee in a summer day program, I gained candid insight into the complex and relatively subjective nature of the responsibilities of community care providers. I often wondered whether or not it was ever appropriate to restrict an individual’s freedom of choice. I was confused about how to balance my duty to care for these individuals while also supporting them in the exercising of their right to self-determination. I often felt uncomfortable allowing the persons I supported to make certain choices and decisions. However, it also felt uncomfortable disallowing someone from spending his/her own money in the way they wanted. This process of ethical decision-making was vague

and confusing. In addition to the feelings of uncertainty about the ethical concerns of my job, I felt pressure to make the right decision. This was accompanied by a similar pressure to be a good employee, and to know when it is appropriate to enact control over someone, and when it is inappropriate to do so. I did not always know what support was available to me as an employee.

**Researcher reflexivity.** Recognizing my personal built-in biases is a critical aspect to the writing of this piece. As a white, middle-class, able-bodied woman positioned as a university researcher, it is necessary to acknowledge the ways in which my identity may influence the collection, interpretation and presentation of data. Maintaining reflexivity throughout the research process will be very important:

Reflexivity is the process of reflecting critically on the self as researcher...it is a conscious experiencing of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the processes of research itself. (Guba & Lincoln, 2008, p. 278)

**Bias.** My previous experiences as a care provider within a community agency setting may be a source of bias. I could unknowingly have certain expectations for the participants' responses, and this could be evident in the way the interview questions are posed. Conversely, my previous experiences in the field may be beneficial because I am familiar with the roles and responsibilities of care providers and the ethical issues they may face. As a result of this previous personal experience, I believe my voice will contribute to a more authentic research experience.

I interpret the job responsibilities of a community care provider to have very strong moral and ethical undercurrents. It is important to recognize that personal experiences of uncertainty and ethical confusion contributed to my desire to explore how care providers describe the ethical

decision-making processes they engage in, and the sources of support available to them to guide these processes.

### **Addressing the Gap**

While there have been recent studies that address decision-making issues in the context of community care, a significant gap in the literature remains. Little is known about how care providers working with persons with ID describe or perceive the ethical decision-making process. “As with many ethical dilemmas, there are no easy answers...Achieving clarity for individuals who use services for persons with intellectual disabilities and their care providers is a difficult process” (Owen et al., 2003, p. 44).

In order for individuals in community care to experience rights support and actualization, the whole picture needs to be considered. Organizational visions and missions of rights promotion form the basis for rights actualization. The policies and procedures of the agency articulate these foundational goals, and come into practice through staff training in rights. It is expected that rights training will automatically transfer into practice and that individual rights of persons with ID are supported and promoted. However, the ethical decision-making processes of care providers is theorized to be a critical factor in enacting the support of individual rights, and it seems to be relatively unaddressed in the literature. By exploring how ethical guidelines translate to the individual level, the entire process involved in rights actualization within community care may become clearer.

### **Research Questions**

The central research questions guiding this study are as follows:

1. How do care providers in residential and day program settings who have had rights training describe the ethical decision-making process?
  - a. Are there differences in the way care providers in residential settings and care providers in non-residential settings describe the ethical decision-making process?
2. How do care providers supporting individuals with ID describe the balance between duty of care and the right to self-determination of the people they support when it comes to ethical decision-making processes?
3. What sources of information guide the cognitive processes of ethical decision-making?
  - a. What sources of information do care providers find most helpful in making ethical decisions?
  - b. What sources of information do care providers think would be helpful in navigating ethical decision-making?

## **Methodology**

### **Purpose of the Study**

The purpose of this research study is to explore the ethical decision-making processes of community care providers who support young and older adults with ID. The subjective and complex nature of ethical decision-making processes was explored through semi-structured interviews with care providers from one community agency.

### **Research Design**

In the present study, a non-experimental, descriptive research design was used. Descriptive studies focus on describing the current sample rather than testing hypotheses about a larger population (Gliner & Morgan, 2000). The descriptive approach is suitable for exploratory

investigations such as the proposed study, as the purpose is not to generalize the results. The use of semi-structured interviews fits with a descriptive approach and allows for in-depth descriptions of phenomena of interest.

### **Participants**

The research participants in this study were recruited from one local community agency called Mainstream: An Unsheltered Workshop. Conducting research in this one agency was partially due to the pre-existing relationship with the agency as a partner of Brock University in the 3Rs Human Rights Project. Thus, all participants in the present study had experienced 3Rs human rights training. In addition, pragmatic concerns of conducting an exploratory study allowed for participants to be recruited from a single agency. The results of this study are not meant to be generalized, as the study seeks to provide a starting point in exploring the issue of ethical decision-making processes. Thus, seeking a more substantial number of participants from multiple agencies was not critical in this case.

**Mainstream.** Mainstream: An Unsheltered Workshop was founded in 1984, and provides services and supports to adults with ID. The focus of the agency is illustrated by its mission statement: “To improve quality of life for people with a developmental challenge by providing a supportive environment that strives to empower individuals with the necessary skills and confidence for lifelong learning and growth” (<http://www.mainstreamservices.com/about.html>). Currently, there are approximately 220 people receiving support from Mainstream in a variety of different contexts.

One of Mainstream’s goals is for all people to “develop their full potential as individuals with respect and dignity, enjoy integration in the community and have the opportunity to prepare



for their future” (<http://www.mainstreamservices.com/images/Philosophies.pdf>). In order to achieve this goal, Mainstream provides supports and services to ensure that persons with ID have the chance to be productive citizens; to reach their potential in the workforce; to access affordable housing that allows them to live an independent lifestyle with supports available; and to be valued members of the community.

**Mainstream services.** The resources and services Mainstream offers have expanded and increased greatly since it was established in 1984. Two streams of residential services are offered for individuals ages 18 and older. These include Supported Independent Living (SIL) and 24-Hour Support programs. The SIL program seeks to provide support for adults with ID who live independently in the community. Specifically, this program encourages and promotes involvement in the community, personal development, and supports individuals in areas of their lives as they are identified. Ultimately, this program assists individuals with various aspects of life and planning while maintaining a focus on rights, choices and quality of life. The 24-Hour Support program also encourages participation in the home/community, skill development, and supports person-specific needs while providing more intensive and ongoing support.

Mainstream also offers individuals with ID a Resource Centre program. This program provides the opportunity for individuals to work in small groups or receive one-to-one support and take part in courses related to occupational and work training, life and social skills, and continuing education. This program offers individuals the freedom to create their own schedule that is interest-based and focuses on specific needs. Options Niagara is a program for young adults between the ages of 18-28 who are transitioning out of school and into life in the community. The focus of this program is to help young adults with ID acquire valuable skills

that will assist in making this transition. Options Niagara helps to identify individuals' personal goals and to assess their life skills and quality of life, from which a specialized plan can be formulated that is specific to these skills and goals. The second part of the process provides assistance to participants who require short-term, specialized support to achieve greater independence but whose needs may not be met through existing services. The specialized supports can assist in building greater independence in Vocational and Community Life Skills. (<http://www.mainstreamservices.com/options.html>)

**Key informant.** As a community partner with the 3Rs Human Rights Project, there was a pre-existing relationship between the researcher's supervisor and Mainstream. This relationship allowed for lines of communication to be opened to propose the idea for this research project. The staff member within the agency who is also a liaison between the agency and the 3Rs project, agreed to act as a key informant in the project. Meetings with the key informant about the purpose and logistics of the research project were helpful in the preliminary stages of shaping the proposal.

### **Recruitment and Sampling**

A convenience sample was non-randomly selected from a total population of 55 agency employees. All Mainstream employees working in residential and non-residential services were given a letter of invitation to participate in the study (see Appendix C). The letters of invitation were distributed by the key informant through the Mainstream internal mail system for non-residential program staff and letters were delivered to residential program staff via the group home mailboxes. Six participants contacted the researcher and expressed interest in taking part in semi-structured interviews. This number of participants was well suited to the present study since

a small number of participants is optimal when conducting studies of an inductive and exploratory nature (Crouch & McKenzie, 2006).

Some of the interviews took place in a private conference room in the Mainstream main office building and some took place at a private lab on the Brock University campus.

Participants' personal data was kept confidential, and only aggregate data was shared with the agency. Personal, identifier information was kept secured in a location on the Brock University campus accessible only to the researcher.

**Inclusion/exclusion criteria.** This study recruited care providers who work in residential services (24-Hour Support and SIL), and non-residential services (Options Niagara). Participants were recruited from both of these work settings because it is hypothesized that they have distinct responsibilities for care providers. By exploring the ethical decision-making processes of care providers in these two different settings, the contextual and subjective nature of the decision-making processes will likely become evident. Responsibilities typically present in residential care settings include fostering life skills, communication and socialization skills and supervision of health and hygiene needs (Community Living Welland Pelham, 2010). For care providers in day program settings, such as Mainstream's Options Niagara and Resource Centre, responsibilities are varied and include - but are not limited to assisting individuals with social skills/interactions and life skills such as choice-making and goal-setting (Mainstream, 2010). Personal care/hygiene is rarely addressed for care providers in day program settings, whereas care providers in residential programs often assist with this aspect of personal care.

The sample was not restricted to care providers based on level of experience. Even though relatively new employees may perceive ethical decision-making processes differently

than more experienced staff, all 55 care providers employed in Mainstream's non-residential and residential programs were invited to participate. In order to account for different experience levels, participants were asked to report their level of experience during the interviews and on a pre-interview demographic questionnaire. In addition, other variables such as the age range as well as perceived range of intellectual capacity of the individuals supported by participants were addressed in the demographic questionnaire and interview questions. The identity of the individuals supported by the participants was unknown to the researcher.

### **Data Collection**

The goal of this research project was to gather a holistic and rich data set from which processes of ethical decision-making can be examined. In order to achieve this, a qualitative method of data collection was applied. "Qualitative research involves the studied use and collection of a variety of empirical materials...that describe routine and problematic moments and meanings in individuals' lives" (Denzin & Lincoln, 2008, p. 4). The method of data collection will now be outlined.

**Semi-structured interviews.** Semi-structured interviews were conducted with six staff in a community care provider role. Two staff were employed within the 24-Hour residential support program, two were employed in the SIL program and two were employed in the Options Niagara program. The interviews were held at the Mainstream head office during work hours and at Brock University in a private lab. Participants were provided with a Tim Horton's gift card worth ten dollars as compensation for their time.

**Interview format.** In order to address the research questions, the semi-structured interview questions sought to assess how care providers describe ethical decision-making

processes, as well as the sources of information that guide these processes (see Appendix F). Participants recruited from residential programs and non-residential programs were asked the same questions in order to assess the similarities and differences in ethical decision-making between these settings. The interviews were audio-taped and ran between thirty five and fifty minutes each.

**Rationale.** In order to assess how ethical decision-making processes are described across care settings, staff from both residential and non-residential programs were interviewed. “The primary aim of in-depth interviewing is to generate data which give an authentic insight into people’s experiences” (Crouch & McKenzie, 2006, p. 485). The purpose of the interview process is to gain rich and detailed data. The semi-structured interviews allowed for the researcher to obtain information about language used by care providers in order for respectful and culture-specific language to be employed. Due to differences in care responsibilities, there may have been different interpretations and descriptions of ethical decision-making processes within these two different service contexts. These potential differences were accounted for by contextualizing the responses within the specific care responsibilities of the particular program setting.

Prior to conducting the interviews, the questions were reviewed by the key informant in order to ensure that appropriate and respectful language is being used. The involvement of a key informant in the formation of interview questions also helped to confirm that the questions were clearly worded and meaningful to the care providers.

**Methodological support for semi-structured interviews.** Dunn, Clare, and Holland (2009) explored substitute decision-making by conducting semi-structured interviews with care providers working in residential homes for adults with ID. A similar methodology was applied in

the present study. The importance of flexibility within the interview structure was highlighted by the authors. Depending on responses given and the direction taken by the conversation, adaptations to interview questions and follow-up prompts will be made.

McAuliffe and Sudbery (2005) explored support-seeking and consultation behaviours in social workers by conducting semi-structured interviews to study ethical dilemmas and how ethically unclear situations are resolved. By applying this method of data collection to the exploration of support-seeking behaviours of social workers, the researchers were able to gather in-depth accounts of the steps taken to resolve ethical dilemmas encountered at work. A similar approach was adopted in the present study in order to illuminate the decision-making processes care providers engage in.

### **Data Analysis**

**Thematic analysis.** “Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within the data” (Braun & Clarke, 2006, p. 79). While thematic analysis is a commonly used theoretical framework to analysis data, there is no common agreement that clearly defines what it is or how it is done: “Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data” (Braun & Clarke, 2006, p. 78).

The current project employed a hybrid approach to data analysis by analyzing deductive and inductive themes. Deductive themes can be identified as theoretically-based or “top down” and inductive themes are identified as emergent or “bottom-up” (Braun & Clarke, 2006, p. 83). “Data collection is guided either by preconceived theories and ideas about what is important, or data collection is guided by the cues that present themselves during the data collection process”

(Ezzy, 2002, p. 63). The present study employed both deductive analysis, and data were coded according to the guiding research questions, as well as inductive analysis, with data coded according to patterns that emerged from the data.

***Phase one: Transcription.*** The audio-taped semi-structured interviews were manually transcribed by the researcher. Analysis of the interview data began during the transcription process. The researcher made field notes that included common/frequent words, phrases and other personal observations that became apparent during the transcription process. The interviews were transcribed within 48 hours of the interview's completion in order to stay on track with the data collection process. In addition, it was important to transcribe while the interview was 'fresh' in order to follow-up on any observations noted while the interview was taking place. "...During data analysis the researcher will typically discover and notice unanticipated issues that have arisen early in the data collection" (Ezzy, 2002, p. 61). Minor changes were made following the first interview as it became evident that certain questions needed to be re-worded and added to gain further insight into the ethical decision-making processes as described by care providers.

Simultaneous data collection and data analysis builds on the strengths of qualitative methods as an inductive method for building theory and interpretations from the perspectives of the people being studied. It allows the analysis to be shaped by the participants in a more fundamental way than if analysis is left until after the data collection has been finished. (Ezzy, 2002, p. 61)

Collecting data while beginning the early stages of analysis allowed the participants' voice to come through in an authentic way. The transcriptions were read over several times each by the

researcher in order to ensure familiarity. “The close attention needed to transcribe data may facilitate the close reading and interpretive skills needed to analyse the data” (Braun & Clarke, 2006, p. 88).

**Phase two: Open coding.** “The first stage of coding during thematic analysis...is often described as open coding” (Ezzy, 2002, p.88). After the transcriptions were read over several times each, the process of open coding began. Crisp (2000) applied the principles of thematic analysis in his study on the perceptions held by individuals with disabilities on health and rehabilitation professionals. The use of open coding in the initial stage of thematic analysis is described by Crisp (2000): “It was, initially, coded openly by scrutinising interview transcripts line by line or word by word; by looking for in-vivo codes, terms used by the respondents; and making comparisons for similarities and differences between events and incidents” (p. 358). A similar process was followed in the present study. Notes were made in the margins of the transcripts to record observations and potential subtext as interpreted by the researcher. Key words and phrases were highlighted during open coding.

**Phase three: Broader themes developed.** Broader thematic ideas were developed out of the notes and patterns highlighted during the open coding stages. Following the open-coding phase, each interview transcript was summarized into a thematic outline. These individual thematic summaries were sent via email to each participant in order to confirm content accuracy. This provided a means of member-checking. This member-check process also contributed to a triangulation of the data. Triangulation of data refers to “the use of two or more theories, methods, or data sources to address the same research question” (Shepard, Orsi, Mahon & Carroll, 2002, p. 335). The technique of triangulation has been used to achieve a sense of



completeness, especially when the phenomenon being studied is complex. Attaining individual confirmation regarding the accuracy of the interview themes was critical in ensuring the data is an authentic representation of the participant-researcher conversation.

By examining recurring themes and similarities across thematic summaries, broader themes began to become evident. Individual themes that were similar in content were grouped together to form broader themes. *Nvivo* computer software was used to organize the data by theme. With the broader themes in mind, the researcher reviewed the transcripts again and sections of the transcripts were coded at various nodes. The nodes were created to represent the deductive and inductive themes. The deductive themes corresponding to the central research questions were explored first, as these reflect the purpose of the present study. These themes include: Care Provider Descriptions of Ethical Decision-making; Balancing Duty of Care with the Promotion of Self-determination; and Colleagues and Supervisors as Sources of Support for Ethical Decision-making.

***Phase four: Inductive themes formed.*** During the selective coding process, themes were confirmed and emergent themes became evident. Initially, the inductive, or emergent, themes were developed by reviewing the individual summaries and highlighting commonalities across the participants. These were dominant ideas that were not probed for, but emerged out of the semi-structured interview conversations. The data were coded using these dominant ideas. The finalized emergent themes include: Balancing Professionalism and Closeness in Staff-Individual Relationships and Process Versus Outcome.

## **Results**

Deductive themes that correspond with the central research questions and inductive themes that emerged from the data will now be reviewed. The major themes that will be presented include Care provider's Descriptions of Ethical Decision-Making, which will review the ways in which participants described ethical concerns and the cognitive processes of ethical decision-making. The theme entitled Balancing Duty of Care and Promotion of Self-Determination, will outline participants' descriptions of factors they consider when balancing job responsibilities with promotion of rights. Strategies used in striking this balance will also be described. Next, the process of rights promotion will be discussed in the theme entitled Process Versus Outcome. The influence of job constraints such as evaluation and time-based pressures and their impact on the ethical decision-making of care providers will be reviewed. Another emergent theme, Balancing Professionalism and Closeness in Staff-Individual Relationships will explore participants' descriptions of the ways relationships with supported individuals are challenged. Finally, the sources of support and information that care providers use to navigate ethical decision-making processes will be discussed in the theme entitled Colleagues and Supervisors as Sources of Support for Ethical Decision-Making.

### **Care Providers' Descriptions of Ethical Decision-Making**

This theme is presented first in order to outline the ways in which participants described the ethical decision-making processes – the foundational aspect of the present study. Ethical concerns and ethical decision-making will both be defined and explained.

**Variability in defining an ethical concern.** The issue of defining an ethical concern is of central importance to the present study because care providers' descriptions of ethical issues

will ultimately impact the ethical decision-making processes they engage in. Participants described ethical concerns as moments in their job marked by conflict, injustice, and inequality. Failure to respect professional boundaries, failure to act in individual's best interest, failure to provide a person-centered approach, and failure to treat individuals with fairness/respect were examples of dilemmas they had experienced themselves and also observed on the job.

Participants will be identified using the codes P1, P2, P3, P4, P5, and P6. The letter 'P' signifies *participant*. The term *supported individuals* refers to persons with ID who are supported by the community agency. This term is commonly used in community agencies.

***Ethical concerns relate to respecting boundaries.*** Care providers supporting persons with ID are in positions of great influence and authority. Due to the level of closeness involved in care relationships, the notion of boundaries is important in establishing what are appropriate and acceptable behaviours. Several participants made reference to the importance of respecting boundaries that are inherent in their jobs. Failing to uphold and respect these boundaries was described as an ethical concern. Participants described ethical concerns as failure to respect moral and professional boundaries.

***Moral boundaries.*** P1 identified ethical concerns as being related to moral issues or concerns that care providers face in their job. This involves respecting the lifestyle choices of the individuals supported:

...I think the ethical concerns comes down a lot to lifestyle choices...It's those decisions...you see people struggle – like, staff – struggle with them, uh you have somebody in, say, a lifestyle that you don't agree with, that you don't think is right, but

you see that that person, you have to look at like, the person as having, that that's their lifestyle, and that's what they choose to do. (P1, p. 12)

Here it is explained that it is common to feel conflicted with the lifestyle choices made by the individuals supported (i.e. poor diet). While this can make the care provider's job more difficult P1 explained that it is important for staff to set their own beliefs and values aside and not to judge the individual's decisions as right or wrong. Similarly, P2 described ethical concerns as being related to cultural and religious aspects of individuals' lives and the need to respect those boundaries:

Well, I don't know, I think it depends on your, your definition of ethics I would think.

But, in terms of what a person needs in – like, in terms of their culture, or their religion, or anything like that, you want to always be aware of boundaries that way. (P2, p. 9)

While P2 commented on the presence and importance of boundaries, it is also stated that describing an ethical concern is dependent on an individual's definition of ethics. This supports the ideology of ethics and ethical concerns as subjective in nature.

***Professional boundaries.*** In addition to respecting the lifestyle choices of individuals supported, one participant described ethical concerns as related to respecting professional boundaries. More specifically, respecting professional boundaries is central to avoiding ethical concerns. P2 provided the example of abuse in group homes as a major ethical concern:

I haven't really run into a lot of ethical things where I've been concerned about crossing boundaries in that way, so you know what I mean? Um, I think you can think of ethical in terms of professional boundaries, like you've heard of different abuse in group homes and stuff like that, which is absolutely disgusting, but, that would be an ethical concern.

This description also suggests that P2 conceptualized ethical concerns as events or issues of a serious nature.

***Failing to support a person-centered approach.*** Two participants described an ethical concern in the context of their job as a care provider involved the failure to support the agency mandated person-centered planning approach to service. Person-centered planning (PCP) involves supported individuals determining their personal goals and working with a care provider to develop a plan to achieve their goals. In sum, the person-centered planning approach provides opportunities for supported individuals to gain control over their lives in ways that are self-determined. P4 described an ethical concern as any circumstance that fails to involve individuals in discussions relevant to their own lives, or in other words, failing to apply a person-centered approach. This was supported by P2 who described an instance in which a supported individual was purposely excluded from a multi-agency meeting regarding his/her life goals. This particular instance was recalled to illustrate an example of an ethical concern. P2 described the negative feelings that resulted from this meeting:

And that really annoyed me because it just, it made me feel horribly uncomfortable and I was, I was encouraged to go ahead just to not be, like, I wanted to be present at the meeting to see what was going on and just to help that way. (P2, p. 21)

Failing to follow a person-centered approach is described as an ethical concern, and in this example, instilled feelings of discomfort in the care provider.

***“That thing in the pit of your stomach.”*** Just as P2 described feelings of discomfort resulting from an unethical situation, P6 described an ethical concern as:

...Something that makes you feel uncomfortable – it's something that you know you're gonna – about to cross a line that probably shouldn't be crossed, or it's a really grey area, and I think you just get that thing in the pit of your stomach where you just know that it's not something that's going properly. (P6, p. 8)

P6 made reference to crossing boundaries, which is similar to descriptions of ethical concerns given by P1 and P2. Describing an ethical concern as a feeling “in the pit of your stomach” is interesting because it seems to imply that ethical concerns have a strong emotional component causing individuals to feel a physical reaction.

***Ethical concern = ethical dilemma.*** One participant referred to an ethical concern as a circumstance when he/she was faced with an ethical dilemma. In this case, an ethical dilemma is understood to be an instance in which there are two undesirable alternatives and there is no clear choice/resolution. When asked to define an ethical concern, P3 referred to an ethical dilemma that was previously discussed during the interview. In this particular incident, the participant had to make a decision as to whether a supported individual with health/diet concerns should be included on a food-related outing. This situation was described as incredibly difficult because P3 had to make a decision about whether or not this individual could make a responsible decision about what to order that would correspond to his/her diet: “And it is [his/her] choice to go, right? So really, it's like, well if [he/she] wants to go, then [he/she] should just go. It's like, well, yeah...but, you know, would you bring an alcoholic into a bar? Right?” (P3, p. 8). While P3 recognized that this individual has the right to be included on this outing, there are also the serious health concerns to be considered. The desire to act in the individual's best interest needs to be balanced with respecting the rights and wishes of the individual.

***Best interests of the individual.*** When asked to define an ethical concern, P5 made reference to circumstances in which care providers attempt to act in an individual's best interest (e.g. encouraging community involvement), but the individual refuses cooperation (e.g. chooses to stay home all day). For example, according to P5 an ethical concern involved balancing acting in the best interest of an individual while also taking his/her wishes into account:

Some of them decide that 'oh I just want to stay at home all day and not do anything' and then they turn – they're just really depressed and then we try to relate it – because you're home all day and not doing anything, and maybe if you like, I'll give them um, like a choice - what if you had a job or something? Or doing a class? And they're like, well I don't want to do that. And they're like, it's my right, you know. And we can't obviously force them to do anything, but we know a lot of the things would be in their best interest.

Despite the fact that the participant has the individual's best interest in mind, he/she is challenged by the individuals he/she supports. This has placed the staff member in a difficult position of trying to respect the rights of the person, while carrying out his/her own job responsibilities. Thus, an ethical concern results when the care provider knows he/she is responsible for promoting community involvement and personal development for the individual supported, however, the individual has no desire to partake in such activities.

P4 also discussed ethical concerns as relating to respecting the best interests of the supported individuals. As an example, P4 described failing to examine all of the possible intervention strategies that will yield the most success, such as not acting in an individual's best interest.

***Fair and equal treatment of supported individuals.*** P4 reported that treating supported individuals differently based on the quality of the relationship, is an ethical concern. Naturally, care providers have different relationships with the individuals they support, and this could influence the type of care provided to the individuals: "...that is somewhat of an ethical dilemma – am I being too hard on this person because they hate me? Or am I being too easy on this individual because, you know, we get along so well?" (P4, pp. 9-10). P4 and P3 both reported the importance of treating supported individuals with respect. Thus, an ethical concern was also described as not treating supported individuals with the respect they are owed.

***Involvement of rights council.*** P5 and P6 described ethical concerns as any circumstance involving Mainstream's rights council. Rights-related concerns can be brought forth not only by individuals supported by the agency but by agency staff as well. P6 described a time in which a supported individual approached the rights council with a concern. The individual's concern was taken very seriously:

Um, I think it's great that we have something like that set up for them and it was quick too – it wasn't something that [he/she] went forward and somebody brushed [him/her] off and was like, 'no...that sounds ridiculous...' They were like, 'oh, okay.' (P6, p. 9)

By commenting on the Rights Council, participants seemed to be making an important link between ethics and rights. In order to uphold the rights of individuals supported, care providers need to be in line with the organizational culture of the agency which defines expectations for ethical practice.

***An elusive concept.*** The variance in definitions speaks to the notion of ethical concerns as being subjective and wide-ranging, encompassing a variety of different elements, and



resulting from the complex nature of care-providing jobs. Participants described ethical concerns as moments in their job marked by conflict, injustice, and inequality. Failure to respect professional boundaries; failure to act in individuals' best interest; failure to provide a person-centered approach; and failure to treat individuals with fairness and respect were examples of dilemmas they had experienced themselves and also observed on the job. These issues are central to the present study and demonstrate the truly vast and diverse nature of ethical concerns facing care providers.

...It's a little word, but it's a big word, right? So...the way I used it then was more like you, talking about, you know, the risks associated with doing this study and participating, and what it means, and the follow-up and the debrief and all that kind of stuff, and the ethics committee and stuff. But ethics is.....it's bigger than that, in real life, right? (P3, p.13)

P3 described the traditional notion of ethics as it is often represented in research – as forms to sign and risks to consent to. However, P3 then described ethics as “bigger than that in real life,” which seems to suggest that ethics is somewhat elusive – that it can be defined on a surface level, but in reality, is a complex term that is difficult to capture using words.

**Descriptions of ethical decision-making processes.** The variance in definitions of an ethical concern is important to consider because it may have implications for participants' descriptions of consequent ethical decision-making processes. Participants reported that they engage in ethical decision-making on a frequent basis as care providers for persons with ID. In addition, there is not often a clear resolution. Just as participants described ethical concerns as being accompanied by “that feeling in the pit of your stomach”, participants also reported ethical

decision-making processes as uncomfortable and awkward. In addition participants described ethical decision-making as a reflective process in which the participant will reflect on the decision before, during and after it is made.

**High frequency.** Care providers reported a high frequency of ethical decision-making resulting from ethical concerns. This is not surprising considering the wide range of ethical concerns staff described encountering in their jobs. P5 referred to a situation in which a supported individual made an inappropriate clothing decision that would risk embarrassment and possible social alienation: "...it's such a dilemma – and that happens in our program all the time and stuff like that" (P5, p. 11). It would appear that within residential programs, there are ethical decisions to be made on a regular basis. Similarly, P6 commented on the high frequency of day to day decisions that need to be made while at work. This became clear upon recalling a situation in which a supervisor was approached for help in resolving an ethical concern:

DF: It seems like there's a lot of day to day little judgment calls...

P6: All the time. (p. 11)

P6 affirmed that ethical decisions are part of daily life as a care provider. When asked to describe a time when he/she felt uncertain about making a decision P5 replied: "There's always constantly like, things that I'm like, well, I don't know what the best decision is...I'm trying to think of an example right now 'cause there's always, like, tons that go on..." (P5, p. 7). Not only do care providers engage in ethical decision-making on a regular basis, but the concerns they are faced with do not often have a clear resolution.

**The 'right' decision is not clear.** P3 described ethical decision-making as a difficult process that results in feelings of uncertainty. In particular, the decision made by the care

provider is often called into question by the care provider him/herself: “There are times when I don’t – I don’t feel like I made the right decision” (P3, p. 10). P6 also referred to this sense of ambiguity in decision-making by describing an ethical concern as “a grey area” (P6, p. 8). In circumstances in which the right decision is not clear to the care provider, ethical decision-making can be an uncomfortable and awkward process.

***Feeling uncomfortable.*** It does not come as a surprise that participants recalled feelings of discomfort that accompanied ethical decision-making processes, as participants also described ethical concerns as moments that evoke feelings of discomfort and unease. One participant described how he/she feels when deciding whether or not he/she should intervene in a conflict situation:

...I don’t feel good about that because I’m like, I can’t tell people to go to their room, do you know what I mean? They’re not my children. And I’m not trying to treat them like children but I do need to take control of the situation. (P3, p. 10)

This participant reported feeling uncomfortable when he/she decided to intervene in order to establish a calm environment. He/she also made reference to the fact that intervening in a situation can feel like a parenting role, which he/she has no interest in taking on. Dynamics of the care-providing relationship will be further discussed later.

P6 described a difficult and uncomfortable ethical decision-making process that involved supervisors and managers within Mainstream due to the severity of the situation at hand:

...It was something that we all struggled with because nobody wanted to step on [his/her] toes and say that you’re not able to make this decision, but in the end, like, you’re put in a

very awkward position and you don't want to see something bad happen to them, so...in the end we had to make the decision for [him/her]. (P6, p. 4)

The decision-making process was reported as difficult due to the fact that P6 seemed to be caught in the middle of an uncomfortable situation. The role of care providers to make ethical decisions is, by nature, a difficult task that is bound to take a toll on the care provider's emotional state.

*Reflective processes.* Several participants described the process of ethical decision-making as involving reflection. This seemed to consist of inner reflection during the decision-making process or post-decision reflection following the decision. P3 described thinking through a decision, wondering if he/she had made the appropriate judgment call: "So that stuff happens where – and then after I'm like, 'was that the right thing to do?' or 'is there a better way that I could go about it?'" (P3, p. 10). Another participant also described ethical decision-making as a reflective process in which care providers should be constantly reflecting on whether a decision they make is for their own benefit or for that of the individual being supported: "But then it's recognizing, okay, is this for me? Or is it for the client? And it has to always be the person-centered approach, and really making sure it's about them" (P2, p. 16). This notion of ensuring a person-centered approach relates to the previous theme, as participants' defined an ethical concern as failing to follow a person-centered approach to service.

Similar to the description of ethical decision-making as involving inner thought processes, it also involved deciding when to intervene in a particular situation: "I guess...I don't make decisions for them. I guess I make decisions for myself of when to react. Do you know what I mean?" (P3, p. 4). Here, ethical decision-making is described as a process in which the

care provider must determine when and how to intervene in a given situation. Similarly, another participant described the ethical decision-making process as involving reflection:

So that can really become a big thought process about what do you do. Is this the right situation or, well I would do it for person A, but for person B, I don't think I should or could or, it's the right strategy for them, right? So it would just become a whole thought process, right? (P1, p. 12)

The emphasis here seemed to be on the thought process during a circumstance in which P1 must make a decision regarding an individual he/she supports. The above quote also alludes to ethical decision-making as being a subjective process.

***Subjectivity.*** During the interviews it was noted that participants described ethical decision-making as case-by-case instances that varied depending on a variety of factors. Participants did not specifically use the word 'subjective', but described the notion of decision-making as little day-to-day judgment calls. For example, P1 described the subjective nature of ethical decision-making:

DF: It sounds like a very case-by-case type thing.

P1: Absolutely... Yeah, it's individual right? Like, you have to consider that person's personal circumstances, and what's going on and you know, other factors that can be contributing to or barriers that they're facing to make that decision, right, to do something.

This quote supports the notion that ethical decision-making is not formulaic; it varies from person to person and is dependent on a variety of factors. This reflects the earlier discussion of the focus of these decisions consisting largely of day-to-day judgments about small issues.

**Differences in descriptions of ethical decision-making.** The reason for recruiting care providers from both residential and non-residential programs was to explore whether there were differences in how care providers in these two types of programs described the ethical decision-making processes encountered in their jobs. While few differences between staff from these services were identified in the interviews conducted for this study it is not appropriate to draw any broad comparative conclusions. The small sample size of six participants and, in particular, the uneven distribution between non-residential staff and residential staff, makes it impossible to draw any conclusions regarding the differences in descriptions of ethical decision-making processes between care providers in these two contexts.

It was noted during analysis that residential participants reported that the ethical concerns faced by care providers in non-residential and residential programs are quite similar in nature. In contrast, non-residential participants reported that the ethical concerns faced by residential care providers are actually quite different than the concerns they face in their job. These differences seemed to be a result of their perception of the job responsibilities of residential care providers.

P1 reported that care providers in residential programs are involved in more, small scale, day-to-day decisions than care providers in day programs due to their heavier involvement in the lives of the clients:

...Care-giving in a day program is sometimes very different than care-giving in a living situation right? You're more medical...like, I mean, you...a decision about like what someone's gonna wear, 'is this appropriate? I don't think it is.' ....there are a million little decisions 'cause there's so much involvement in someone's life. (P1, p. 24)

P1 perceived the decision-making for care providers in residential programs to be more frequent due to supported individuals having a lesser ability to make informed decisions than individuals supported in Options Niagara, where it is thought that the individuals are more capable of making independent decisions. Another participant inferred that care providers in group homes not only engage in ethical decision-making processes at a higher frequency than care providers in non-residential programs, but that the care providers make decisions *for* individuals they support: “And we’re not necessarily in a role like every group home, or something like that where we’re making constant decisions all day for somebody” (P2, p. 16). This could be because it is believed that individuals supported in residential homes require more intensive supports due to a lower intellectual capacity.

P4 claimed that it is more important to respect the wishes of the individual within residential service supports due to the fact that the care provider is working in the individual’s home. Non-residential programs have a more instructional format, and often are geared towards supported individuals’ involvement in the community in a volunteer or employment role: “Basically, it’s – it’s their home, so it’s important for me to respect their wishes as opposed to directing them, which, um, they do at the....vocational placements. They’re working in vocational, and they’re living in residential” (P4, p. 12). However, despite the fact that P4 reported that the job responsibilities in residential and non-residential supports are different, this participant reported that the ethical concerns faced by care providers are the same (i.e. ensuring clients receive adequate support and are given as many choices as possible, maintaining a person-centered approach).

In summary, participants described ethical decision-making processes as occurring frequently and resulting in feelings of uncertainty and discomfort. Participants also described ethical decision-making as a reflective process in which they reflected upon whether the right decision had been made. Such processes were described as subjective and as dependent on various factors.

### **Balancing Duty of Care and Promotion of Right to Self-Determination**

...It was something that we all struggled with because nobody wanted to step on her toes and say that you're not able to make this decision, but in the end, like, you're put in a very awkward position and you don't want to see something bad happen to them... (P6, p. 4)

The above quotation seems to effectively capture the complex nature of ethical decision-making processes care providers often find themselves engaged in. While there seems to be a sense of caution to avoid making decisions for an individual, the desire to protect and ensure the well-being of a supported individual simultaneously exists. The balancing act of protecting individuals from harm while promoting their right to self-determination is described by participants through rich, detailed accounts of personal experiences as care providers at Mainstream.

**Importance of independent decision-making.** Despite the subjective and difficult nature of balancing the duty to care for clients while simultaneously promoting their right to self-determination, participants unanimously reported that it is in the best interest of the individual for staff to encourage independent decision-making. While care providers claimed that it would be easier and more convenient for them to step in and make decisions for the individuals they



support, they described the importance of supporting the individuals to engage in decision-making processes on their own. P1 provided an example:

...is it tempting – don't you wish you know, you could just be like, 'no, you're having salad and a piece of chicken for dinner, not a pizza.' Do you wish you could do that sometimes? Yes. But...it is more understanding that they need to make their own choices for sure. (P1, p. 11)

This notion is supported by another participant who explained that the desires of the supported individuals should be considered to be most important, regardless of what appears to be the easiest decision/choice for staff:

...You always have to make sure you're – it's up to them at the end of the day whatever decisions you make, 'cause sure it would be easier if I said, 'yeah let's just do it this way' and probably some of my guys would be like, 'okay sure, why not?' Right? But...it has to always be the person-centered approach, and really making sure it's about them. (P2, p. 16)

Here, the participant described the importance of care providers encouraging supported individuals to make independent decisions, even if they consider them to be a poor decision. This relates to the importance of maintaining a person-centered approach as was discussed by several participants. Providing care and protection as well as opportunities for independence and freedom of choice is a very subjective process, and relates back to the care providers' descriptions of ethical decision-making as subjective in nature. Because individuals require varying levels of support, it seems to be an ongoing decision-making process for staff members to determine when and how to intervene to assist.

**Knowing when and where to ‘draw the line.’** Situations that require care providers to balance duty of care responsibilities with the promotion of the right to self-determination usually involve an ethical decision-making process. While the concepts of protecting an individual from harm and promoting the right to self-determination seem to exist in contention, participants described ways to account for both concepts in their ethical practice.

**Dignity of risk.** A determining factor influencing when and how staff intervene in situations is whether the decision made by a supported individual poses a risk to his/her health/well-being or that of others. This is related to Perske’s (1972) concept of ‘dignity of risk’ as previously discussed in the literature review, which states that persons with disabilities need to experience situations of risk just as persons without disabilities do. Failing to do so will impair their human dignity.

P4 explained the decision-making process used which determines whether or not it is appropriate to intervene in an individual’s decision-making: “If it’s not going to cause any great harm, it doesn’t really matter. It’s only when someone puts themselves or someone else at risk that you have to step in. Otherwise, who cares?” (P4, p. 4). While this quote may suggest a sense of irresponsibility or carelessness (“who cares?”) it would seem that P4 supported Perske’s notion of dignity of risk: supporting the right of persons with disabilities to engage in situations with what the staff member perceives to be minor risk. P4 also stated that it is important to compromise with the supported individual, always offering desirable alternatives. Similarly, another participant who works in residential services stated, “...if they don’t want to do it, is it really impacting their quality of life? If not, then what’s the big deal?” (P6, p.18). The example

of cleanliness of residential homes was used to illustrate the importance of being able to determine whether a situation poses a real risk to individuals:

...Yeah, your dishes can be dirty and sitting in your sink and yeah, you can have a leftover pot of lasagna sitting on your counter. As long as you're not eating it so that you're not getting sick, I don't care if it sits here today. If you don't feel like cleaning it up, then I mean, let's just aim to get it done by the end of the week so that you're not getting a disease or something. (P6, p. 18)

In this example, the participant explained the cognitive process of evaluation in which the amount of actual risk posed to the residents of the home was weighed. Since there were no immediate or serious risks to leaving dirty dishes in the sink, the participant did not view this situation as requiring intervention. Should the conditions of the kitchen pose health risks to the residents, it would likely have yielded a different outcome.

**Ensuring informed decisions.** In addition to the process of weighing out the risks and benefits of a situation, participants reported that they often mediated the process of balancing duty of care with the promotion of self-determination by making sure that the supported individuals are making informed decisions and are aware of the potential consequences of each decision. One participant explained this process:

...We try to give them all the information they need and make sure we work through it with them, with their family, whatever we can do, but ultimately they're going to make their own decision at the of the day, um, regardless, right? (P2, p. 9)

The overarching attitude of the participants seems to be that supported individuals should be ultimately in control of their own decision-making. However, this does not seem to mean that

care providers should be absent from these decision-making processes. For example, a participant explained how he/she balances his/her duty to provide care and support while also encouraging self-determination:

...It's just a matter of reminding her of what a good choice is, and what not, but she is making the decision. They're always making the decision. But you do exert influence because it's your – it's part of your job, is to keep people healthy and safe, and all that kind of stuff, but you don't like, you're not like, 'no!' you know? It's their home ... there's something called free will, right? (P3, p. 6)

Here, the participant explained the importance of acknowledging the responsibility of care providers to assure the well-being and safety of the individuals they support, while at the same time respecting the right of individuals to make independent decisions. P6 reported mediating this process by educating the supported individuals about the potential consequences of their actions. This was reported as a critical aspect to respecting the right of supported individuals to make their own decisions, while also making efforts to protect the individuals from harm.

**Strategies used by care providers.** Care providers described balancing the duty of care and the promotion of self-determination as a subjective and often difficult process. As noted by the participants in the present study, there are many factors that influence how care providers make decisions to achieve this balance.

*Negotiation and compromise.* P4 described the ability to compromise and negotiate a feasible alternative with the supported individual as a critical component of protecting the supported individual from harm while allowing him/her to engage in self-determination. P4 used the example of a situation that required a change in plans due to inclement weather. Negotiating

with the supported individual and explaining the change in plans were described as critical in these circumstances. P4 also explained the importance of providing as many alternatives as possible in order to promote choice for the supported individuals. While the original plan may have had to be changed, P4 described the importance of protecting the well-being of the supported individuals, while also providing alternative choices.

***Creativity in problem solving.*** Similar to the strategy of negotiation and compromise, is the ability to solve problems in creative ways. Not only is it critical to be able to negotiate with supported individuals, but P4 also stated that it is important to provide creative alternatives to provide choice. P3 supported this by stating that care providers need to be creative to avoid difficult/challenging situations: “So now I just try to be creative and think of other things to do....So it’s about being creative and trying to think of alternatives that are also attractive to the individual” (p. 9). P4 reported that not only is problem-solving a necessary strategy when trying to balance duty of care and promotion of self-determination, but it is necessary when faced with unavoidable last minute changes in plans, which are common occurrences for care providers.

***Encouraging self-advocacy.*** When asked about providing care and protection for the person supported while also supporting that person to make his/her own decisions, P5 reported that by encouraging clients to be self-advocates (i.e. to speak up for themselves) there is less pressure for care providers to balance their duty of care and the promotion of self-determination. If supported individuals can engage in self-advocacy, they can then self-protect by speaking up for themselves. “...We always advocate on, like, speaking up for themselves” (P5, p. 6).

Participants reported that the process of balancing the duty to provide care for supported individuals while also promoting the individuals’ right to self-determination is a subjective and

complex task. All participants expressed that it is important to encourage supported individuals to engage in independent decision-making. While participants acknowledged that it would be easier to make decisions on behalf of supported individuals, they agreed that it is more important to respect an individual's decision. Several participants reported that the risk of harm to supported individuals and others is an important consideration when balancing protection with rights promotion. If the individual is not putting themselves or others at risk of serious harm, staff members reported being less inclined to intervene. Participants also described that by informing supported individuals about the potential consequences of their decisions and choices, staff members are able to influence the decision-making process without completely interfering in the process. Other strategies that participants reported as helpful included negotiation and compromise with the supported individuals to reach a safe and desirable alternative. By providing creative options, staff members can encourage safer alternatives when the risk of harm is impossible to avoid.

### **Process Versus Outcome**

During analysis, recurring references were made to the process of promoting the rights of supported individuals. This issue of 'process' is the crux of the present study, as the process of rights promotion is ultimately being explored through the examination of the ethical decision-making of care providers. The 'outcome' is essentially the end result or conclusion of any process. The progression of reaching the outcome is deemed 'process.' There seem to be various factors that influence whether the 'outcome' or the 'process' is most important to staff members. These factors will now be reviewed.

**Time pressure.** There is no doubt that care providers are faced with many demands and schedules to accommodate on a daily basis. Time pressures and schedule demands placed on them impact their decision-making in various ways.

...When you're working and you're doing these quick conversations and everything is moving at a fast pace that before I think it was the mindset of it's easiest – just do whatever's easiest to get through the day, kind of thing. Not necessarily what's best for them. (P6, p. 16)

Here, P6 reflected on the ways in which care providers considered process versus outcome prior to the introduction of rights training for staff. Learning about how to support the rights of individuals seems to have prompted care providers to think twice when making certain decisions. P6 stated that the easiest option is not always what is best for the individual being supported.

Similarly, P2 acknowledged the fact that there are times when it is tempting to make decisions for individuals, and individuals may not even protest this. "...Sure it would be easier if I said, 'yeah let's just go do it this way' and probably some of my guys would be like, 'okay...sure – why not?' right?" (P2, p. 16). However, experiencing rights training has encouraged care providers to think twice when making decisions: "But then its recognizing, okay, is this for me? Or is it for the client?" (P2, p. 16). While ignoring the process may allow for decisions to be made more quickly, this does not ultimately serve the client's best interest.

**Evaluation pressure.** There also seems to be evaluation pressure placed on staff when it comes to achieving a certain outcome or checking a certain task off a list. The fear of negative evaluation by supervisors and managers appears to be a factor in determining how care providers manage process versus outcome. Thus, the underlying issue is whether following through with

the process can result in care providers being “in trouble” with their managers. P6 illustrated this issue by sharing how ‘outcome’ can be valued more than ‘process’:

DF: What are the consequences – or, are there any consequences - for you in your job if a person you support makes a decision that results in something going wrong?

P6: ...There have been times where you receive a backlash by letting them make their own choices if it fails because, um, it just looks bad on paper...So yes, they’re adults and yes they can make their own decisions but not really when it comes down to it. It needs to be us doing it and telling them, ‘we don’t care, you’re still going to get in the car and come with me.’

DF: Right, it sounds like what you’re saying, like, the onus is more on you as a staff to make sure decisions are made a certain way?

P6: Yes, absolutely. Absolutely. (p. 6)

Despite the desire of the care provider to support individuals to engage in independent decision-making, the risk of achieving an unsatisfactory outcome (and thus, consequences from supervisors) seems too risky to allow. Consequences may be experienced by care providers as a result of allowing supported individuals to make independent decisions. For example, a participant described an instance in which a supported individual approached him/her expressing a desire to run an errand independently and the staff member complied. When the errand was made incorrectly, the staff member received criticism from the supervisor for allowing the supported individual to run the errand without support. In this case, the outcome was not potentially dangerous and seemed to be valued as greater than the process. The participant



reported that this is because certain outcomes appear more attractive on paper (i.e. to be able to document in a report that all tasks or errands were completed).

**Promoting growth and independence.** Also influencing this issue of process versus outcome is the desire of care providers to promote independence and growth in the individuals they support. P1 recalled the importance of supporting individuals to be independent despite the temptation to assist in the process:

P1: And that's really hard, especially in [residential programs], we face that even, with um, social, like, people having a social life....it was very tricky because we want to support people to be independent...instead of like, you know, picking them up and taking them [to the movies].

DF: Right.

P1: Right, so where does that independence come? ...Where are you building the independence, if you're just doing it for somebody?

DF: Right.

P1: ...There needs to be that, that individual, like responsibility and choice over that too.

(p. 11)

Here, P1 illustrated the benefits for the supported individuals that can result from focusing on the process. While performing tasks for an individual may be interpreted by care providers as helpful care-giving behaviour, it does not benefit the supported individual in the end. Ultimately, P1 outlined the critical element of responsibility that can be gained by supported individuals when they are encouraged to act independently of care providers.

**Double standards.** Focusing on the outcome of a situation rather than the process itself seems, in part, to be a result of holding individuals with disabilities to a different standard than people without disabilities. In other words, there seems to be a double standard in place that has resulted from pressures placed on care providers to do their job in a particular way, or to achieve a particular outcome. Care providers may feel time or evaluation-based pressure in their jobs which could result in supported individuals experiencing less choice, less flexibility and less ownership over their lives. P6 provided an example that aptly demonstrates this concept:

I think sometimes we expect them to be perfect little models of these people that we're telling them, 'this is who you're going to be because this is what is normal and this is what everybody should be, so you need to fall into this category. And everything you have to do has to match up.' And I think we put a lot of pressure on them that they have to perform perfectly every day. That it's wrong to have, like, an off-day, or it's not okay to feel like you're sick and you want to stay home. Like, if I'm sick and I don't want to go to my...appointment I could call...and say I am not coming in today because I don't feel well – I'm gonna re-schedule. Where we don't really give them the opportunity in most cases – well, I mean...not everybody gives them the opportunity in most cases, to do things like that. (P6, p. 16)

It seems that spur of the moment decisions are not a common occurrence for individuals living in group homes due to the fact that their lives are intertwined with the care providers' job responsibilities. P6 offered another example that illustrates the pressure on care providers to achieve certain outcomes, but also how persons with disabilities are held to a different standard than persons without disabilities:

We have to plan something to get them out in the community, get them out of their home and do something, which, even that is something that I struggle with as to - if it was me and this is my Saturday, and I've worked ten days in a row, do I want to get out of my house at nine o'clock in the morning and go do something for the sake of doing it? No. I want to lay on my couch and in my pyjamas and I don't want to move all day. Whereas we're telling them, 'come on, get up! We're gonna go to the movies, we're gonna go for lunch, we're gonna do this,' like, and it's like a bribe to get them to come, but if they don't want to come, we shouldn't be made to feel like we didn't do anything on the weekend because we didn't take them out. (P6, p. 14)

Using the example of a scheduled weekend activity, P6 voiced frustration over the fact that while it is socially acceptable for him/her to spend a lazy Saturday at home on the couch, often it is not acceptable for individuals in group homes or supported living programs to do the same. Another source of frustration seemed to be based on the fact that by respecting the desires of the supported individuals, P6 may face consequences from the supervisor as a result. This is a clear example of how the outcome of a situation can be perceived to be more valuable than the process.

P4 also commented on the need to avoid this double standard: "Generally, things that happen in our lives happen with our knowledge certainly, and most often with our consent. Shouldn't be any different than people that live in group homes" (P4, p. 7). P4 seemed to be suggesting that due to the fact that individuals are living in group homes, it can seem more acceptable for decisions to be made without their consent or involvement.

While P6 and P4 commented on the need to avoid double standards, P5 offered a different perspective on the issue:

...There's no consequences...everybody knows that they could get away with murder here (laughs) kinda thing, and like they'll – or one person will [break a house rule] and it's not allowed really, and then there's like a threat – oh, then they'll get evicted, but they never do, and stuff like that. That's – that's the one part of the program that I think needs work on – is sometimes, like, the discipline of following through kinda thing.

'Cause there's no consequences. Everybody knows if they do something wrong, there'll be like, a little bit and – a little bit of a consequence... (p.6)

P5 seemed to suggest that there should be more consequences in place for individuals in residential programs. However, herein lies the double standard: persons with disabilities are often held accountable for their actions to a greater degree than persons without disabilities. As a result of individuals with disabilities being supported by community agencies, they are often under close supervision and not able to engage in risk taking situations and make decisions that individuals without disabilities experience on a daily basis. P6 seemed to be promoting this double standard, asserting that persons with disabilities should, in fact, face more consequences for their actions, consequences that are not often experienced by persons without disabilities.

While P5 suggested that persons with disabilities are often held to a different standard than those without disabilities, he/she also seemed to suggest another type of double standard: persons with disabilities are more often able to get away with things that persons without disabilities may not be able to. In the above-mentioned quote, P5 suggested implementing consequences for rule-breaking because house rules are not adequately enforced. This claim suggests that persons with

disabilities are not held as accountable for their actions as much as this participant believed they should be.

Time/schedule pressures and evaluation pressure experienced by care providers were reported as factors influencing whether staff members value the growth process involved in encouraging supported individuals to be independent, or achieving a particular outcome. Fear of negative evaluation by a supervisor or manager was reported when staff members value the process of rights promotion versus attaining a specific outcome. Participants also reported that while they desire to promote experiences of growth and independence for the individuals they support, they also desire to assist in the process. Several participants made reference to the fact that supported individuals may often be held to a different standard than persons without disabilities. This could be due to the time and evaluation-based pressures experienced by staff which translates into supported individuals experiencing less choice and ownership over their lives. One participant highlighted a different double standard, claiming that supported individuals are more likely to escape consequences or punishment (i.e. for not complying with house rules). There seems to be a contradiction present in which persons with disabilities are reported to be held to higher and lower standards than are those without disabilities.

### **Balancing Professionalism and Closeness in Staff-Individual Relationships**

Many participants stressed the importance of establishing a professional relationship with the individuals they support. While this was communicated as being valued by staff members, it was also described as difficult to maintain. Relationships between staff and the individuals they support can become complicated for several different reasons.

**“It’s my place of work, but it’s their home”.** For care providers working in residential programs, there seems to be difficulty in balancing a professional relationship with the level of closeness often required in supporting individuals in their homes. Due to the fact that the staff member’s work environment is a client’s home, it is easy to form close relationships with the individuals. One participant described this notion:

...We’re close. It is a professional relationship – in the sense, I mean, you know, you have to sort of...set up a certain boundary in the sense - have your own personal life outside of work because, you know, that’s healthy. But the relationships that we have...especially in the 24 hour support, it’s very intimate in the sense that I’m working in their home. That’s their home. I mean, it’s my place of work, but it’s their home... (P3, p. 2)

Another participant (P5) also described the relationship with the supported individuals as close, but then in the next response stated that he/she has to remind them that they are not friends:

I have to always tell them that I’m staff – I’m not their friend; that I can’t be having like, chit-chats with them when I’m at home ‘cause I want to keep my home life at home and work life here. (P5, p. 3)

While the participant expressed a desire and need to establish a boundary between work and personal life, he/she then explained that due to the nature of the care-giving relationship, the individuals he/she supports can seem like family:

...If any of them are in danger or sick or whatever, like, it’s almost like they’re my family too...but I am so close to the people that I work with, that if anything were to happen to them, it – it’s very traumatizing for myself. (P5, p.3)

The participant then clarified that his/her relationship with the individuals supported is not the same kind of relationship as he/she has with family members and this is because there is an aspect of professional duty attached. It is clear that the relationship between care providers and the individuals they support can be complex and complicated as care providers struggle to balance a level of professionalism in a work environment that is inherently intimate.

On the other hand, care providers in non-residential programs seemed to have less difficulty establishing a professional relationship with the individuals they support. The distinction between 'staff' and 'friend' seems to be easier to maintain in a non-residential program setting because the job responsibilities are less personal/intimate than in residential programs. As one participant explained:

...in [a residential program] you're a lot more involved – you're going to the medical appointments, you're going to help them with their finances, you see them, you know – daily, or a couple times a week....whereas in Options Niagara, you probably see someone three times a month. So you're, they just know you a lot better, 'cause you just shared so many more experiences with them....so it is a different relationship for sure. (P1, p. 6)

Here, the participant explained that care providers experience different types of relationships with the individuals they support in different kinds of programs. This seems to be due not only to the difference in job responsibilities, but also because non-residential care providers spend less time with the individuals they support.

Relationships between care providers and supported individuals also seem to be complicated when staff and the individuals they support are close in age. In these circumstances, the distinction between staff and friend can become blurred for the person being supported.

Professional boundaries are important to enforce in these situations even though, outside of a work context, staff members may have been able to be friends with the individuals they support.

**References to a parent-child dyad.** During analysis, it was noted that several staff made reference to parent-child relationships when describing their interactions and relationships with the individuals they support. These references came about in two different ways: staff as the ‘parent’ and supported individuals as the ‘children;’ and supported individuals as the ‘parent’ and staff as the ‘children.’ This was an interesting emergent finding related to the relationship between care provider and supported individual, as staff members were able to see themselves as taking on a parental role, but also ascribed a parental role to the supported individuals.

**Staff as ‘parent’.** One participant (P6) who is employed in a residential program made a comparison between a typical parent-child relationship and the care provider-care receiver relationship experienced at work:

...It’s almost like a parent-child relationship – you have to let them fail to grow and to learn from their mistakes, um, so it really does become a fine balance of where to draw the line and where you should stop and where you should step in. (P6, p. 5)

Another participant (P3) referred to a parent-child dynamic as he/she negotiates his/her role in the lives of the supported individuals: “I can’t tell people to go to their room, do you know what I mean? They’re not my children. And I’m not trying to treat them like children, but I do need to take control of the situation” (P3, p. 10). This participant seemed to be struggling with the fact that as a staff member, there are responsibilities that seem to mirror the role of a parent. While the participant acknowledged the fact that he/she is not a parent to the individuals in the house, there are still times in which parental-type actions may be appropriate (e.g. intervening when



there are conflicts between individuals in the house). However, the participant clarified that supported individuals should be treated in an age-appropriate manner and not as if they were their children.

P5 referenced a family-like dynamic when describing the relationship between staff and supported individuals: "...it's almost like they're my family....it's not like my kids, but I am close to the people I work with...." While P5 did not suggest that the individuals supported are like his/her children, there was mention of a familial relationship.

***Supported individuals as 'parents'.*** While several participants made references to the care provider and supported individual dyad as a 'parent-child dyad' in certain respects, the opposite also emerged. One participant explained that treating the supported individuals as if they were his/her own parents is a way to improve practice:

...If this was my mom, if something happened to my mom and she had an acquired brain injury, and now needed to live in a group home, would I want someone to be treating or talking to my mom the way that this is playing out? So I try to keep that in the back of my mind just 'cause everybody deserves respect and dignity and we want to try and make sure that happens. (P6, p. 3)

Later on, the same participant drew another comparison to the supported individuals as parents or close relatives:

I would assume everybody is like my parent, or somebody that I knew in my personal life. If you're looking at these people as an actual individual who has respect, who has feelings, who has dreams and they want to be treated with dignity, I think that helps you provide them with the care that you need to. (P6, p. 10)

By picturing the individuals supported as his/her parents, P6 described this as a strategy to improve ethical practice.

In summary, participants working in residential programs reported greater difficulty balancing closeness with professionalism in their relationships with supported individuals than participants working in non-residential programs. It would seem that the distinction between ‘staff’ and ‘friend’ is easier to maintain within non-residential programs, due to the fact that the job responsibilities of care providers involve less personal/intimate care. Participants also described the relationship between staff and supported individual by referring to a parent-child relationship. Some staff reported that some job responsibilities mirror the role of parents, and the care-providing relationship with supported individuals has some similarities to a parent-child relationship. However, staff did acknowledge that supported individuals should be treated in an age-appropriate manner. Conversely, another participant reported that treating supported individuals as if they were his/her own parents help to provide a good quality of care.

### **Colleagues and Supervisors as Sources of Support for Ethical Decision-Making**

Team Leaders, supervisors and co-workers were identified as the primary sources of support/information that care providers consult when they are faced with a difficult ethical concern. Participants reported a steady flow of discussion and conversation when it came to resolving ethical concerns. In addition, staff members reported engaging in shared learning processes with colleagues in which suggestions and advice could be offered. In addition to supervisors and colleagues, the culture of the agency itself was also referenced as a source of support when staff members encounter difficult ethical issues. These ideas will now be reviewed in further detail.

**“There’s a constant flow of information and dialogue”.** The majority of the participants agreed that Team Leaders (on-site supervisors) and co-workers are primary sources of support and information when resolving an ethical concern. In particular, it was reported that the constant flow of communication among staff members provides an environment in which daily ethical concerns and decisions can be discussed and resolved: “...We communicate a lot...we come in and if we had something that came up, we usually share it with our team leader or supervisor, whoever happens to be in the office, just to run things past them” (P2, p. 12). P5 also commented on the frequency of instances in which advice is sought from supervisors: “...There’s always constantly like, things that I’m like, well, I don’t know what the best decision is, and it’s good that, like, I have my team leader and my supervisor to go to” (P5, p. 7).

When asked who the participant would speak to first about questions regarding an ethical concern, P5 responded that the first line of communication is with supervisors and then advice from colleagues may be sought: “Well sometimes, like, we’re in the office and I’ll be telling them, like, you know this just happened and I don’t know what to do, and then I’ll get like, my – the other support workers’, um, opinion.... (P5, p.8). A constant flow of communication seems to allow staff to learn from each other and to gain insight from their peers’ previous experiences.

**Processes of shared learning.** Participants described the communication with their colleagues as engaging in processes of mutual learning. Sharing previous work experiences with colleagues seems to be beneficial for care providers, as they are able to act as resources to one another. Often times, a colleague has experienced a similar concern and is able to offer advice as to how to resolve it: “...it’s just talking through and using your staff as really your resource to talk, ‘cause a lot of people have been in similar situations and that kind of thing” (P2, p. 11).

Care providers also reported that their colleagues will often help to brainstorm possible resolutions:

We – we're very good, like, with communicating and emailing and talking to each other, and just sharing resources and ideas, or, if I've run into a hiccup with a parent, saying, you know, this is what's going on, does anybody have any ideas? (P2, p. 11)

It would seem that the level of communication regarding ethical concerns is so high because work colleagues and supervisors are easily accessible when care providers have questions or concerns regarding an ethical issue:

...At any given point, if there's a question – if there's something that you're uneasy or question, there are three or four people that you can reach out to immediately. Just to act as a sounding board or if you feel uncomfortable making a determination, to send it to them, and see what they think. (P4, p. 8)

Not only did participants report frequent support-seeking from their peers and supervisors, P4 reported that there are many different people available to approach regarding an ethical concern. In addition to this, one participant reported that talking to co-workers was not only a means of sharing advice, but a means of sharing feelings and discussing how certain situations affect him/her. This seems to be another way for care providers to gain insight into certain ethical scenarios. For example, one participant described a common interaction between staff members: "On a day to day level...sometimes you talk to your co-workers about it – 'how do you deal with this?' You know, like, 'do you ever feel this way? Do you ever feel -?' 'Gosh, I find that frustrating'..." (P3, p. 11). This seems to suggest that colleagues may also be used as emotional resources to empathize with each other by sharing their feelings.

**Small versus large scale ethical concerns.** Depending on the severity of the ethical concern, care providers may seek support or information from different people. Smaller, more common, day-to-day issues can be discussed with co-workers and large scale ethical concerns can be discussed at a more formal staff meeting where managers are present:

It depends on the magnitude, like...ethical issue can be like a little, wee, or like a huge thing...if it's something that's of *concern*, you know...you're like, 'this isn't right' or 'this is – this doesn't seem right.' Or 'how are we gonna make this happen without doing this,' or whatever – something big, then you – we talk about it at staff meetings but with management there, you know? (P3, p. 12)

**Discussion of ethical concerns with supported individuals.** While work colleagues and supervisors were reported to be primary sources of support/information, one participant reported that he/she viewed the individuals he/she supports as sources of information to resolve ethical concerns: "...Sometimes there's those conversations where, and depending on your relationship with the person, you can have that conversation with the person as well. Of saying 'you know what? I feel I'm struggling right now about what's going on here'..." (P1, p. 14). Being able to talk through an ethical concern with a client to further understand their perspective is contingent on the quality of the relationship between the staff and supported individual, and the environmental surroundings they find themselves in at that moment. For example, if the staff and client find themselves in a chaotic situation, it may not be possible or even appropriate to talk something through with the individual. Speaking with the supported individuals themselves can help staff to understand the thought processes of the individuals which can be helpful in future situations.

**Organizational support for ethics.** While discussing ethical concerns and providing examples of ethical decision-making, two participants referred to ethics as being engrained in the Mainstream culture. This ‘culture of ethics’ seems to act as a source of support for ethical practice. P1 discussed the ‘engrained’ culture of ethics as a source of support in balancing care provision and protection while also supporting individuals to make their own decisions: “And I think here, within this organization, like, that’s just engrained, so I think it’s less of a struggle here because we know it’s so engrained in our philosophy” (P1, p. 11). The culture of the agency also was described by P3 as an abstract, universal standard that seems to guide practice: “...There’s this kind of abstract, this like, dream, this, you know like, our philosophies and our mission and the way that we do things, and it’s inherent in what we do” (P3, p. 8). The philosophy of the agency is described as an abstract ideal that care providers embrace and that ultimately guides their actions. This organizational culture of ethics is reported to translate from the macro level to the micro level of interactions between care providers and the individuals they support: “I do believe all the employees that I’ve worked with anyways – at Mainstream – have that core inherent ethical way about the way that they interact with people and support people...” (P3, p.10). Here, it is suggested that care providers at Mainstream are inherently ethical, which seems to be linked to the organizational culture of the agency. P1 confirmed this saying, “yeah it’s like it’s engrained in the culture here...we have a certain way of doing things, and people here are very...very good about just knowing that...it’s just part of life here...” (P1, p. 23).

**Staff suggestions of sources of information.** One participant (P1) who works with younger individuals indicated that it would be helpful to have greater knowledge of the individuals’ personal values, apart from those of their parents. It is common when interacting

with younger supported individuals for the parents' values to be more apparent than those of their children. This may be because the youth have not yet differentiated their values from those of their parents. Perhaps the age and life stage of the young person acts as an underlying factor for this. In addition, individuals receiving support may not have had enough life experience to be able to define what their personal values are. Thus, it may also be difficult for younger individuals to articulate their personal values. By understanding the values of the supported youth, it may help the staff to better assist them in establishing and attaining their life goals.

Similarly, another participant (P2) who also supports younger individuals suggested that parents of clients might be useful sources of information and support. While there is some cooperative involvement from parents, the more the parents are involved and on board with their child's goals/plans, the more beneficial it is to the success and outcomes achieved by the child.

When asked whether there were any sources of information that could be used to help in making ethical decisions regarding supported individuals one participant (P3) suggested receiving training in ethics would be especially helpful. In particular, opening up discussion on the topic of ethical decision-making and dealing with ethical concerns, would help to gain a consistent understanding of ethics as a critical element of practice. One participant who works in a residential program reported that having access to supported individual's uptake reports would be help in making ethical decisions about the individuals supported. Uptake reports are documents completed by agency staff when an individual begins to receive support from the agency. These documents provide background information about the supported individuals and contain records of important information regarding in the individual's history. Accessing these reports could assist staff in making more informed decisions. For example, if the care provider

knows that an individual has a background that suggests he/she could present a threat to others, the care provider may make decisions about community outings in a different way than for an individual with no history of posing a threat to others.

When asked whether there were any desired sources of support that could be used to assist in ethical decision-making processes, another participant who works in the SIL program reported that he/she thought an external governing board would be helpful:

I wish there was something that we could do on the outside...something set up that we could appeal to where it wouldn't affect my job, because there have been certain things that have come up where – and it's come down from [senior administration] and I don't agree with it... (P6, p. 11)

An external board would be used for staff to appeal to if they disagreed with a decision made by managers at Mainstream. While the participant thought that this would be useful, he/she also commented on the fact that this would be unrealistic and it would be difficult to protect employees' job security within the agency.

Frequent communication between staff members was reported as being the primary source of information care providers used to resolve difficult ethical concerns. Staff reported that insight and advice are gained from their co-workers and supervisors. Colleagues and supervisors were viewed as resources and staff reported engaging in processes of shared learning with them. Several participants reported that there is an engrained sense of ethics within Mainstream's organizational culture which helps in the support of ethical practice and the balance of care provision and promotion of self-determination. Participants reported a variety of sources of



information that would be helpful in resolving ethical issues they face in their job including training in ethics and ethical decision-making.

## **Discussion**

### **Purpose of Study**

The purpose of this research study was to explore the ethical decision-making processes of community care providers within a local community agency supporting youth and adults with intellectual disabilities. This area has been relatively unaddressed in the literature and is a critical piece in understanding how organizational policies and procedures get translated into supporting the rights of individuals on a day-to-day basis.

While persons with ID have historically been abused at a higher rate than the population at large (Sobsey, 1994), large strides have been made towards equal access to human rights which has improved the quality of life of persons with ID. Codes of ethical conduct that guide practice within the human services field rely on the support and protection of human rights. Thus, rights can be argued to be foundational to ethics and ethical practice. While professionals in the fields of psychology and social work have ethical codes that are clearly outlined, professionals in community care and services for persons with ID do not have a universally accepted code of ethics (Owen et al., 2001). This leaves professionals in community care largely on their own to establish the nature of their relationships with supported individuals. There is an inherent tension for care providers to balance their duty to provide care and protection for the individuals they support, while also promoting the right of the individuals to engage in self-determination. While there have been studies that have explored the systematic support of individual rights (Mullins, 2009), ethical decision-making has not been explored as it relates to

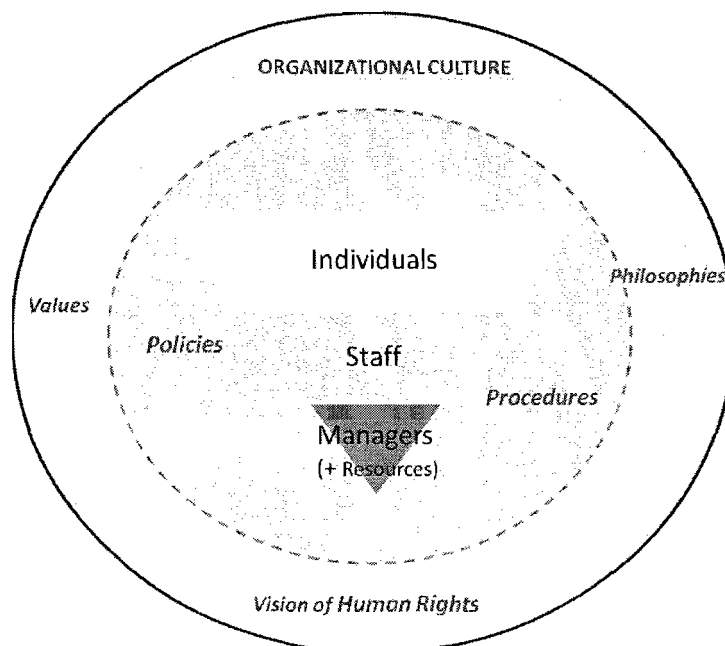
the promotion of human rights for persons in community care agencies. In particular, the present study sought to explore the ethical decision-making processes of community care providers in an agency in which staff members have been trained using the 3Rs Human Rights Training Program.

The present study sought to explore this critical intersection of ethical decision-making and human rights for persons with ID. The results of the interviews with direct care providers provide insights into the thought processes that guide the ways they make ethical decisions regarding the individuals they support.

### Guiding Conceptual Framework

In order to discuss the central themes and demonstrate how they connect and relate to one another, a conceptual model has been developed. This model is designed to illustrate how the various components of a community agency for persons with ID interact and influence one another. After the themes were developed from the interview data, this model was created in order to clarify how each theme relates to the bigger picture. Each theme will be located and highlighted within the model.

Figure 1: Conceptual model for results.



It was important to outline the structure of the agency and the broader organizational culture in which it is positioned. With Mainstream's strong rights mandate, it was imperative to represent the philosophies, values and policies/procedures that support the human rights of the persons it supports. The inverted pyramid represents the structural elements of the agency. The smallest piece at the bottom of the pyramid represents the management staff and resources used by managers. This includes any supervising staff, upper management, the Mainstream Rights Council, and staff training initiatives/programs. The middle section of the pyramid represents the care-providing staff employed by the agency. The top of the triangle represents the individuals supported by the agency. This is the largest section of the pyramid because the persons supported are the ultimate focus of the agency.

The inverted pyramid representing the agency itself is positioned within a sphere representing the organization's policies and procedures that govern the practice of the agency employees. A more abstract, ephemeral sphere consists of the philosophies and values of the agency, and the vision and mission for support of individual rights. The level between the agency and the organizational culture acts as the practical interface between the two. The two spheres are separated by a dotted line which indicates a bidirectional flow of influence. Elements of the organizational culture may influence the agency structure and, conversely, interactions occurring at the agency level may also influence the organizational culture of the agency. This model will be used to frame the results and provide a reference point in understanding how the themes are interrelated.

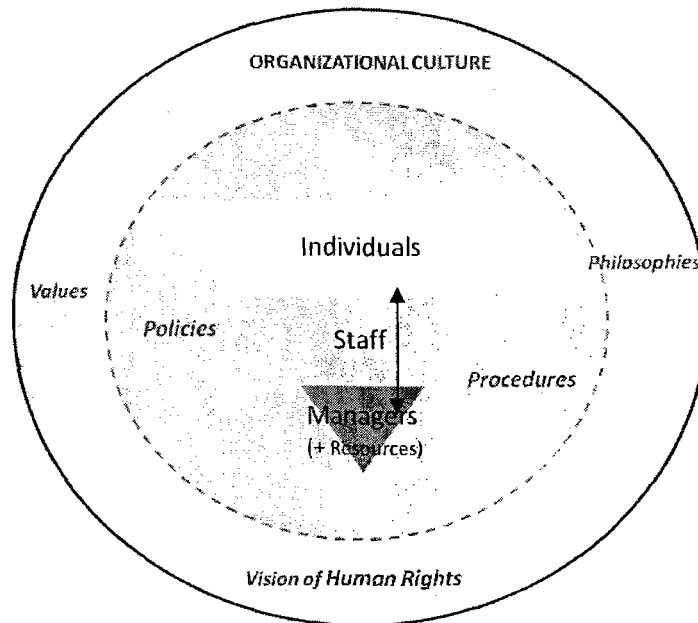
### Care Provider Descriptions of Ethical Decision-Making

**Variability in defining an ‘ethical concern’.** “As with many ethical dilemmas, there are no easy answers and achieving clarity for individuals who use services for persons with intellectual disabilities and their care providers is a difficult process” (Owen et al., 2003, p. 44). McAuliffe and Sudbery (2005) defined ethical dilemmas as situations in which there are two undesirable alternatives, and no one right answer is clear. This sense of the ambiguity of ethical dilemmas is replicated in the present study.

The variation within the participants’ definitions of an ethical concern speaks to the core of this entire study. In particular, it emphasizes and reaffirms what is found in the literature about ethical concerns as being subjective and wide-ranging, encompassing a variety of different elements, and resulting from the complex nature of care-providing jobs. Participants described ethical concerns as moments in their job marked by conflict, injustice, and inequality. Failure to respect professional boundaries, failure to act in individual’s best interest, failure to provide a person-centered approach, and failure to treat individuals with fairness/respect were examples of dilemmas they had experienced themselves and also observed on the job.

Two participants discussed ethical concerns as any issue that is brought forth to the Mainstream Rights Council, making a connection between ethics and rights. This is interesting to note and supports the bidirectional flow connecting the individuals supported by the agency, and the managers and resources they control.

Figure 2: Conceptual model highlights the direct linkage between supported individuals and management.



The arrow in Figure 2 demonstrates the direct flow of influence from management to individuals supported, as well as the flow of influence from supported individuals to the management level.

**Descriptions of ethical decision-making processes.** The Australian Association of Social Workers define ethical decision-making as “the process of critical reflection, evaluation and judgment through which a practitioner resolves ethical issues, problems and dilemmas” (AASW, 2010). This combination of reflection, evaluation and judgment on behalf of a practitioner or staff person is the core issue this study explored. Corey, Corey and Callahan (1998) discussed the relatively subjective nature of ethical conflicts, and the ways professionals in the psychology field respond to them: “Because ethical codes cannot be applied in a rote manner, practitioners are more likely to respond to a dilemma based on their personal values and practical considerations” (as cited in Cottone & Claus, 2000, p. 279). While ethical codes may establish a set of objective principles and rules for conduct, resolving ethical dilemmas seems to

have a subjective and personal component. “It is rarely possible to find definitive answers to ethical problems presented by people with ID” (Wilson, Clegg, & Hardy, 2008, p. 617). The complex nature of ethical dilemmas and decision-making is addressed within the literature, and the results of the present study align with these findings.

Similar to the variability in defining an ethical concern, the participants’ descriptions of ethical decision-making processes seem to confirm that processes of ethical decision-making in the context of community care for persons with ID are subjective and often difficult for care providers to navigate. In addition, care providers reported that ethical decision-making occurs at a high frequency, and is often accompanied by feelings of discomfort and confusion. These descriptions of ethical concerns and ethical decision-making processes support the case made by Polkinghorne (2004) for a judgment-based practice of care. As previously discussed in the literature review, the Aristotelian concept of *phronesis* refers to a sense of ethical duty that is context-driven and involves constant reflexive monitoring of practice (Frank, 2006). Care providers described ethical decision-making processes as subjective and reliant upon the particular circumstances of the immediate environment. This seems to correspond with the concept of *phronesis* and a judgment-based practice of care which value ethical and intuitive knowledge of care practitioners. While codes of ethical conduct may suggest guidelines for a particular practice of care, it is often left to the care providers to use judgment-based practice in resolving ethical concerns.

**Comparing ethical decision-making in different work contexts.** While the difference in the descriptions of ethical decision-making are not conclusive due to a small sample size, it was observed that care providers supporting individuals in residential programs (24 hour support

and SIL) seemed to provide more detailed examples of specific instances than care providers supporting individuals in non-residential programs (Options Niagara) when describing ethical concerns and ethical decision-making processes. This could be due to the fact that there were only two participants from the non-residential programs, and therefore less data to work with. However, when staff members are providing support to individuals in their home, there is automatically a different level of intimacy that may not be present in non-residential support programs, where individuals are receiving more vocational-type support and less personal care. Further research with a larger sample would be necessary to explore the differences in descriptions of ethical decision-making processes between residential and non-residential programs.

The subjective nature of ethical decision-making has implications for how care providers balance their duty to provide care and support to individuals, while also promoting the rights of these individuals to engage in self-determination and make independent choices/decisions.

### **Balancing Duty of Care and the Promotion of Self-Determination**

The dilemma of protecting supported individuals from harm while also supporting them to engage in self-determination is central to the present study. This issue is inherent in the nature of the work for care providers supporting individuals with disabilities, especially in the organizations that adopt a rights-based service philosophy. One of the central research questions addressed this issue: How do care providers working with individuals with ID describe the balance between duty of care and the right to self-determination of the people they support when it comes to ethical decision-making processes? While it is known and understood that care providers are faced with this dilemma, the critical piece was to understand *how* this dilemma is

conceptualized and addressed by care providers. In other words, what mediates this process of balancing duty of care and promotion of self-determination?

All participants described the importance of promoting independent decision-making among the individuals they support, even though the individual may make what the care provider deems to be a poor decision. Participants described a process of figuring out when and where to ‘draw the line.’ Participants indicated that weighing out the risks to an individual’s safety/well-being with the benefits of self-determination is critical in determining when to intervene in an ethical concern. If there is no potential for the individual to be seriously harmed or to cause harm to another person, care providers will not intervene. Thus, this seems to align itself with Perske’s (1972) concept of dignity of risk. However, the determination of what is deemed risky is still left to care providers. Thus, risk is ultimately filtered through individual staff members and their subjective interpretations of what constitutes risk. Staff members’ interpretations may also be influenced by external pressures such as time constraints and fear of negative evaluation by supervisors.

In her investigation of the systemic aspects of rights training for persons with disabilities in a community agency that has implemented the 3Rs Human Right training, Mullins (2009) discussed barriers faced by care providers in supporting the rights of persons with disabilities. Mullins reported that, for care providers, overcoming ‘grey areas’ is a major barrier to supporting the rights of persons with disabilities. These grey areas were described by participants as situations in which they were not sure whether a rights restriction was present. Specifically, participants reported that it was unclear whether supporting an individual’s rights would conflict with their job responsibilities as a staff member. For example, one staff member explained, “If



somebody is going to say, 'I'm doing this no matter what, it's my right to do it', but they're not safe, then it's my responsibility to say no" (Mullins, 2009, p. 127). Most participants in Mullins' study reported that they did not think they were able to support the rights of the individuals supported by the agency when the choices made by the individuals put them at too high of a risk (Mullins, 2009). While Mullins (2009) focused more specifically on the support of individual rights, her findings seem to be supported by the results of the present study: Unless an individual was putting him/herself or others at risk of harm, care providers generally refrain from intervening.

Another way care providers balance care and the promotion of self-determination is to assist individuals in informed decision-making. Care providers described the importance of ensuring that the individuals they support are as informed about the nature and consequence of each decision as possible. By educating individuals about the potential consequences of a decision, the care provider can provide guidance while also allowing supported individuals to make independent decisions. However, this is still a difficult balance to strike.

Participants described some strategies used to mediate their duty to provide care while also allowing for self-determination. These included negotiating and compromising with the individuals and engaging in creative problem-solving. Being able to think on the spot and offer desirable alternatives in the face of a changed plan is described as an important skill for care providers to have. One participant indicated that by promoting self-advocacy, the supported individuals will be able to advocate and protect themselves by asserting their rights. This requires further exploration in future studies, as it is somewhat vague and was only mentioned by one participant.

### **Process Versus Outcome**

While it may be assumed that care providers are primarily responsible for upholding the rights of the individuals supported by the agency, there are other factors that influence this process. Staff members are expected to manage time constraints and fulfill job responsibilities while promoting the rights of the individuals they support. Thus, 'process' refers to the way a task is completed and 'outcome' refers to the end result (i.e. whether or not a task is completed). It is the process of rights promotion that is being explored through the examination of the ethical decision-making of care providers.

This emergent theme addressed the complex relations that underlie the interactions between managers, staff members and individuals supported by the agency. One participant suggested that the 3Rs Human Rights training taught staff the importance of taking the time to allow for a decision-making process to unfold, rather than just focussing on the outcome. This is an important observation and gives credence to rights training initiatives implemented by Mainstream. However, the same participant then went on to provide examples of circumstances in which he/she had experienced pressure from supervisors to focus on the outcome rather than the process. These statements seem to be in contradiction with one another. First, the participant commented on the benefits of rights training: learning to recognize the value of allowing a process to unfold at the hands of the supported individuals. The participant then recalled instances when he/she faced pressure from supervisors to support individuals in ways that did not align with the vision and mission of rights dictated by the agency. It seemed that the threat of not completing a task properly was the main factor in mitigating against process and in favour of outcome. In these instances, there seems to be a disconnect between organizational culture and

staff conduct. While the culture supports the process of supporting individual rights, these time and evaluation pressures are pragmatic elements associated with the realities of balancing the needs of a group of individuals. These pressures may be influencing the conduct of staff in ways that do not align with the agency's philosophies, and at times may mitigate against the focus on the process. Managers and supervisors that fail to ascribe to the agency's vision of support of individual rights may also act as factors that inhibit this process from occurring.

Figure 3: Conceptual model highlighting the influence of management on staff conduct.

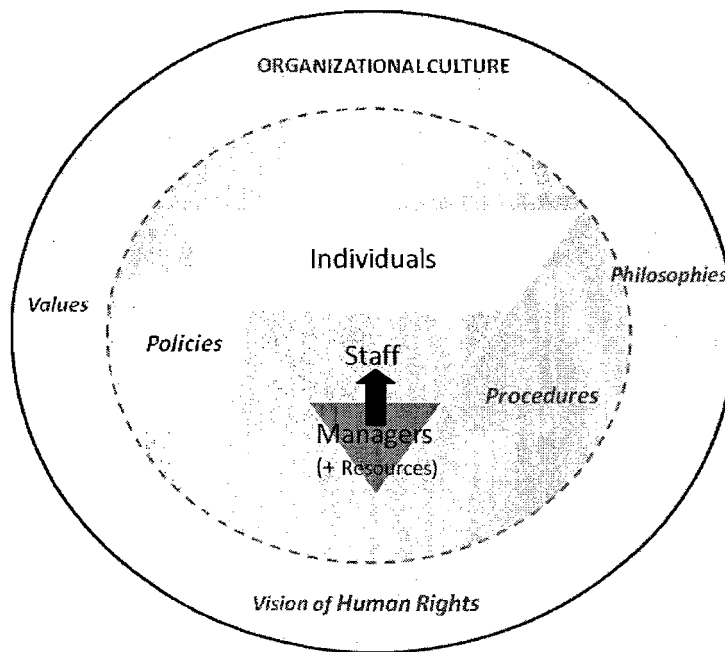


Figure 3 demonstrates that in spite of the organizational mission and vision for support of individual rights there may be pressures from supervising staff on care providers to accomplish a particular goal or to complete a particular task. This is signified by the dominant arrow which emphasizes job pressures originating from management, which seems to overpower the influence of the organizational culture. In other words, the emphasis is on the outcome and not the learning/growth that may happen as a result of the process. In addition, a strict schedule may be imposed on staff with little space for flexibility. Jenkinson et al (1992) stated “decision-

making...is usually tempered by practical realities” (p. 1). Factors such as lack of resources, organizational structure, and demanding workloads may influence the extent to which supported individuals participate in decision-making that affects their own lives.

When something is done *for* an individual, it is arguably a less valuable experience than if the individuals do something for themselves. It has been argued that by eliminating the chance of failure, the care provider disallows supported individuals the chance for independence and growth. Ultimately this infringes on their human rights. This discussion is central to Perske’s (1972) concept of dignity of risk.

The issue of process versus outcome leads into a discussion about double standards that are often in place for individuals with disabilities. For persons who live in group homes, there are certain standards put in place that are unavoidable simply due to the fact that it is a shared residence and there are other people’s rights to consider. For example, it would be appropriate to implement a no-smoking policy in order to respect the health of the other residents while the rights of the smoker may be violated. However, the line becomes blurry when it comes to other issues. For example, where does the line get drawn when a supported individual who is under the influence of alcohol decides to make a personally risky decision? If the care providers are aware of the individual’s condition, should they allow him/her to leave the house? And what consequences does the staff member face as a result of avoiding double standards and holding persons with disabilities to the same standards as persons without disabilities by allowing supported individuals to make decisions completely independently? These are important questions that need further investigation to be addressed.

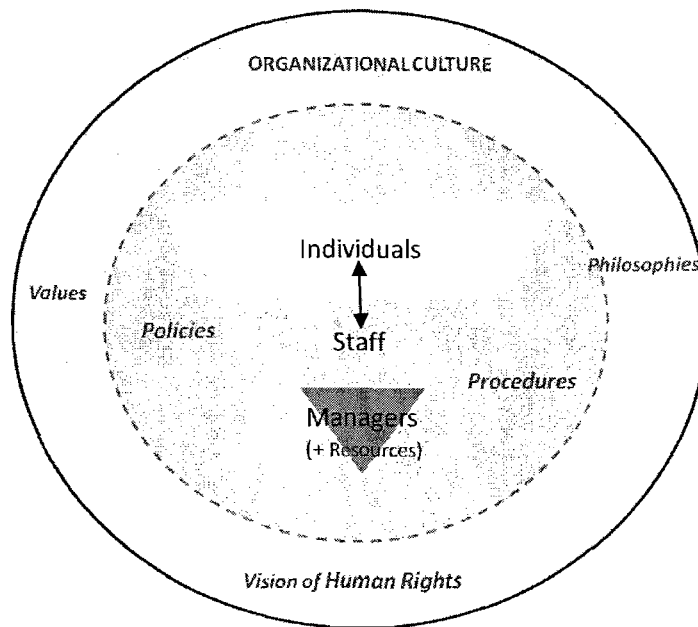
### **Balancing Professionalism and Closeness in Staff-Individual Relationships**

Care providers working in residential programs described establishing a professional relationship with supported individuals as being a more difficult process than did care providers in non-residential programs. This does not come as a surprise that care providers supporting individuals in their homes (24-hour support and SIL) have more personal care responsibilities than care providers who support individuals in non-residential environments. This seems to relate to the findings of Owen et al. (2000) who found that individuals receiving support in residential programs deemed physical touch including hugs, touches on the leg, and even kisses from care providers to be acceptable. The authors suggested that a universally accepted ethical standard that guides professional practice may assist in preventing care providers from taking advantage of the vagueness of the care provider role. In a follow-up article Owen et al. (2001) discuss the absence of such a universally accepted code of ethics for community care professionals supporting persons with ID. While the mere existence of a universal standard of ethics is not expected to completely prevent the small percentage of professionals from knowingly engaging in inappropriate relationships with those they support, it could encourage an awareness of and monitoring of these professional relationships.

Several references were made by participants to their relationships with supported individuals using 'parent-child' language (care provider as 'parent' and as 'child'). It was not clear if this was due to the care-giving role mimicking that of a parent-child relationship, or whether the perceived child-like intellectual capacity of the supported individual influenced this. Conceptualizing supported individuals as children not only implies a breach in professionalism, but it also has serious rights implications. Supported individuals have the right to be treated with

dignity and respect and, if they are being treated as children, this could constitute a rights infringement. This issue was not explored in depth in the present study, but would be an interesting future research study. Participants also reported the perception of supported individuals as parents requiring care. These references may reflect participants' attempts to conceptualize their relationship by relating their professional relationship to other, more universal care-providing contexts. This then calls the uniqueness of the staff-individual care relationship into question.

Figure 4: Conceptual model highlighting the staff-individual relationship.



The highlighted arrow in Figure 4 identifies where this theme is 'located' within the conceptual model. It would be interesting to explore how much of the staff and supported individual's relationship is dictated by the standard put in place by the agency (what translates from the organizational culture) and how much is dictated by the staff's personal understanding of what constitutes an appropriate relationship.

**Colleagues and Supervisors as Primary Sources of Support for Ethical Decision-Making**

Participants reported a high frequency of discussion and conversations about ethical concerns and decision-making processes occurring between co-workers and with Team Leaders and other supervisors. This seems to suggest that these complex ethical decision-making processes are not being treated as forbidden topics of discussion, and are being taken seriously by care providers and supervising staff. Mainstream employees reported that they speak openly about these challenging issues, not leaving them unaddressed or dismissing them as unimportant. At the present, it seems that discussions surrounding ethical issues are welcomed and even encouraged by management and supervisory staff.

One participant suggested that an ethics training session would be a useful source of information to help resolve ethical concerns. This is an interesting suggestion and calls into question whether the teaching of resolutions to complex and subjective ethical processes is a valid possibility. While training programs in ethics for professionals in services for persons with ID would be useful, such programs would not be sufficient in and of themselves. Ongoing discussion about ethical issues would be critical due to the complex and situational nature of ethics in practice. There is value in providing an environment and time in which these issues can be addressed and discussed, and care providers may be able to become more comfortable in their decision-making.

Figure 5: Conceptual model indicating the flow of information when resolving ethical concerns.

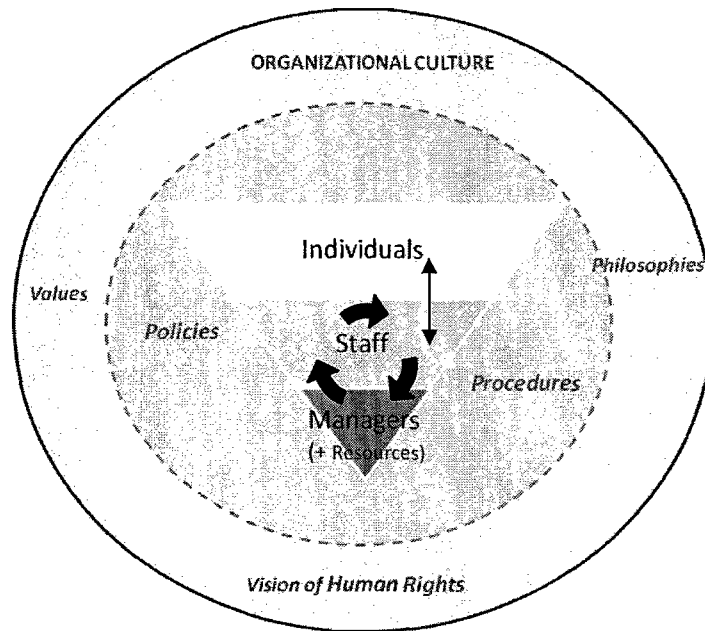


Figure 5 illustrates the flow of information in resolving ethical concerns. The cycle of arrows that circulate between staff and managers indicates the primary sources of information and support that care providers use to resolve ethical concerns: organizational policies and procedures provide guidance while supervisors and colleagues provide consultation and support. In addition, one participant discussed seeking information from the supported individuals themselves in order to understand their perspective when resolving an ethical concern. This is represented by the single arrow between staff and individuals.

Participants in both residential and non-residential programs referred to a cultural ‘engrainedness’ of ethics within Mainstream. This was suggested to be present in the agency’s philosophies and policies, and adopted by the staff. The bidirectional arrows connecting staff and organizational culture represent this engrained ethical culture that staff reported as supporting and guiding ethical practice.



It would be interesting to explore the extent to which similar support processes are used in other agencies that have adopted a commitment to a rights-based service philosophy. This notion of a culture of ethics should be further explored in order to understand how organizational policy translates into day-to-day ethical practice.

## **Conclusions**

### **Strengths and Limitations**

The present study used semi-structured interviews to gather detailed accounts of ethical decision-making processes used by direct care providers. This method of data collection contributed to a rich data set.

Little is still known about how care providers working with persons with ID describe or perceive the ethical decision-making process. The present study has contributed to this gap in the literature and the results of this study have the potential to offer critical insight into how individual rights are not only upheld, but also conceptualized by care providers in community care settings. The present study has also helped to form a basis for additional research to be done in this area.

A limitation of the present study that is important to consider is the uneven representation of residential and non-residential staff in the participant pool. Out of the six care providers who responded to the letter of invitation, two were employed in a non-residential program. Having only two representatives from non-residential programs limited cross-program descriptive comparison.

While transcribing the interviews, there were several occasions when inadvertently leading statements or questions were used. It is important to acknowledge these as sources of

bias. There were also instances in which further probes would have been useful to elicit more detail and specificity from the participants. Because this was my first experience conducting interviews, I noticed a gradual improvement in my ability to probe and deviate from the interview guide, when appropriate, over the course of the six interviews.

Due to the fact that this study relied on convenience sampling, the type of person who volunteered to participate in the study may be generally more eager or interested in ethical issues than the average employee, based on the fact that they volunteered their time to participate. This could be considered a biasing factor, however, because the results of this study are not meant to be generalized, this may not necessarily be a real limitation.

### **Implications**

The results of this study are well-positioned to be applied to the development of a training program for frontline care providing staff supporting individuals in community care settings. In particular, common ethical concerns faced by care providers could be established and consolidated to form the basis of an ethical decision-making staff training initiative. By working through examples of commonly occurring ethical concerns through small group discussion and role play scenarios, care providers may be able to develop practical skills that will help them in resolving ethical concerns.

### **Areas of Future Research**

As previously stated, this exploratory study sought to illuminate the ethical decision-making processes of community care providers as a way to open this issue up to discussion and further research. Many areas of future research became evident during analysis.

The nature of the relationship between care provider and supported individual emerged in the present study in various ways. The field of services for persons with ID is unusual given the fact that staff may work with the same individuals for decades. While this was not a specific focus of this particular study, it is clear that more research could be done in this area that would illuminate this complex dyad. Many research questions remain and include: What guidelines are there for care providers to determine what is considered to be an “appropriate relationship”? How is a care-providing relationship in community care similar to or different from professional care-providing relationships in other human services fields? How are long-term care-providing relationships navigated? How does the quality of the relationship between staff and client impact rights actualization and ethical decision-making? Owen et al. (2000) addressed some of these questions and concerns in their article on acceptable boundaries and call for “a model that defines and guides appropriate consumer-staff relationships” (p. 46). Professional care providers are expected to take on multiple roles (i.e. friend, teacher, parent, counsellor) which can be confusing not only for the supported individuals, but also for care providers themselves. Further research that focuses on how care providers in residential programs balance professionalism and closeness with the individuals they support would also be necessary to further shed light on this complex issue.

Future studies that focus on exploring the concept of dignity of risk would be important to develop. “Expanding or restricting the range of choices available to an individual is based on a systematic risk/benefit analysis” (Schloss, Alper, & Jayne, 1993, p. 223). This risk/benefit analysis is a complex process that care providers may engage in without conscious awareness due to time constraints and other practical realities that interfere with the support of individual

rights. While the present study explored the decision-making of care providers when it came to protecting supported individuals while also promoting self-determination, this area remains unclear and requires specific investigation at the individual level of staff-individual interaction.

Care providers working with young people in non-residential programs brought up interesting issues related to working with Transitional Aged Youth (TAY) who still live at home with their parents. There are clear age-specific issues that apply to youth as they begin to differentiate from their parents, and establish themselves as adults. While there is considerable literature regarding the transition from youth to adulthood for young persons with disabilities (Blacher, 2001; Janus, 2009), it would be interesting to further explore how TAY engage in processes of differentiation from their parents. P1 discussed the desire to know and understand the values the TAY subscribe to, and how this could be helpful for care providers' ethical decision-making processes. Developmental tasks (i.e. identity and self-concept development; entrance into the workforce; and independent living) are often more difficult for youth with disabilities than for youth without disabilities (Blacher, 2001). Future research could explore the various factors that are most prominent in young peoples' successful experiences of differentiation from parents/families. Exploring how youth with disabilities develop and define their own values is an important area of research that has great implications for the quality of life experienced by transitional aged youth.

It would have been useful to conduct follow-up interviews with the participants in order to continue the conversation following descriptions of complex ethical concerns and decision-making processes. A follow-up interview would have given participants the chance to flesh out the meta-cognitive aspects of their thinking. Follow-up interviews would have also provided the

opportunity to delve into the issues that emerged from the initial interviews. Posing hypothetical ethical dilemmas to the participants and asking the participants to work through them would also have been instructive.

It is important to recognize that all participants in the present study experienced the 3Rs Human Rights Training Program, as Mainstream is a partnering agency of the 3Rs. Thus, it would be interesting to explore how care providers who have not participated in the 3Rs training would have described ethical decision-making processes. Perhaps the candid examples of ethical dilemmas provided by the participants in the present study were a result of their experience with the 3Rs training. When rights violations are highlighted and discussed in a training context, ethical concerns may become easier to recognize and discuss. It would be interesting to conduct an exploratory-comparison study in which care providers from two different agencies (one that applies the 3Rs training and one that does not) could be interviewed. Differences in the staff members' responses would be interesting to explore and may provide insight into the efficacy of the 3Rs Human Rights Training Program.

### **Contribution to the Literature**

Recent studies have addressed decision-making issues in the context of community care. However, care providers' descriptions and perceptions of ethical decision-making processes remain a relatively unknown area of community care research. The purpose of this study was first and foremost to explore the complex interactions present in the care-providing relationships of staff within a rights-based community care agency and the individuals they support. In particular, the role of care providers in supporting the rights of the individuals they support was the underlying issue explored. The ethical decision-making processes care providers engage in is

a critical piece in the broader picture of supporting individual rights. This study explored how ethical guidelines translate from the organizational to the individual level, illuminating some of the processes involved in rights actualization for individuals supported by a community care agency. In addition, the present study has provided a starting point for further research and contributed to a foundation on which more important discussion can take place. Conversations and discussion regarding ethical concerns faced by care providers in community agencies are critical. By establishing a language for professionals and academics in the field to use to discuss such important ethical issues that are inherent in community care, conversations can begin and further growth and progress can occur. For care providers at Mainstream, discussing issues with colleagues and supervisors has encouraged an approach to rights-based resolution of ethical concerns.

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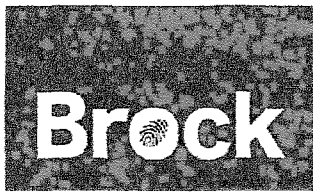
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Certificate of Ethics Clearance for Human Participant Research

DATE: 11/04/2010

PRINCIPAL INVESTIGATOR: OWEN, Frances – Child & Youth Studies

FILE: 10-070 - OWEN

TYPE: Faculty Research STUDENT: Danielle Fry  
SUPERVISOR: Frances Owen

TITLE: Exploring the Ethical Decision-Making Processes of Community Care providers

**ETHICS CLEARANCE GRANTED**

Type of Clearance: NEW

Expiry Date: 11/30/2011

The Brock University Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 11/04/2010 to 11/30/2011.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 11/30/2011. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Michelle McGinn, Chair  
Research Ethics Board (REB)

**Note:** Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

Appendix B:  
Organizational Confidentiality Consent Form

Researchers: Danielle Fry, CHYS; Dr. Frances Owen, CHYS

Project title: Exploring the Ethical Decision-making Processes of Community Care providers

I understand that the purpose of the proposed research project is to explore the ethical decision-making processes of community care providers who support young and middle years adults with Intellectual Disabilities.

I understand that the researchers will collect data by conducting semi-structured interviews with care providers employed by *Mainstream: An Unsheltered Workshop* and *Mainstream Non-Profit Housing Project*. In addition, a subsequent questionnaire will also be distributed to care providers employed by this agency. I understand that the interviews and completion of the questionnaire will be undertaken by *Mainstream* staff during their paid work hours.

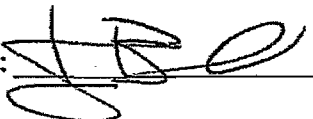
I understand that I will be provided with a thematic summary of the results of this research project.

I understand that participation in this research project will be strictly confidential, and participants **will not** be identified by name in this thesis or in other publications or presentations. Confidentiality will be breached only if there is threat of harm to self or others, disclosure of reasonable suspicion of abuse and subpoena of the researchers; records.

I understand that *Mainstream: An Unsheltered Workshop* and *Mainstream Non-Profit Housing Project* **will** be identified by name in this thesis, and in other publications and presentations.

[ ] Yes, I give permission for the above-mentioned researchers to identify *Mainstream: An Unsheltered Workshop* and *Mainstream Non-Profit Housing Project* in this thesis and in other publications and presentations.

Name: Kevin Bersuick Position at Mainstream: Executive Director

Signature: 

Date: Oct. 4/2010



### Appendix C: Letter of Invitation to Participate in Interviews

Study Title: *Exploring the Ethical Decision-making Processes of Community Care Providers*

**Researchers:** Danielle Fry, Child and Youth Studies & Dr. Frances Owen, Faculty, Child and Youth Studies, Brock University.

I would like to take this opportunity to invite you to participate in a study that seeks to examine how community care providers who support individuals with Intellectual Disabilities (ID) make decisions about how best to support these persons. In particular, this study seeks to explore the how care providers think through ethical decisions and dilemmas as they work through issues related to supporting individuals.

Participating in this study includes an interview. The interview will include questions about your role as a care provider within Mainstream and ethical decision-making within the context of your job.

Your participation will be voluntary, can occur during work time and you may withdraw from the study at any time without penalty. You will receive a \$10 Tim Horton's gift card as compensation for your time. Participants will have the option of being interviewed at Mainstream or at Brock University. All personal data will be kept strictly confidential. Only the researchers named above will have access to the information you give throughout participation in this study. Your name will not be associated with any comments provided when the results of the study are reported and published. Your decision to participate, or not, will in no way affect your employment or standing within Mainstream. We may use direct quotations from interviews but all identifying information will be removed from quotations that are used. Your involvement in this study involves only minimal risk (i.e. feeling uncomfortable disclosing some information). All information disclosed will remain completely confidential.

Your participation in this project is extremely important. It will provide insight into the ethical decision-making processes of care providers who support individuals with ID.

If you are interested in participating in this study, please contact Danielle Fry by email at: [df04ju@brocku.ca](mailto:df04ju@brocku.ca) or by phone: 289-969-4282.

Thank you for your consideration,

Danielle Fry

This study has received ethics clearance by the Brock Research Ethics Board (REB - 10-070 - Owen). If you have any questions or concerns about your participation in the study, you may contact Danielle Fry or Frances Owen ([fowen@brocku.ca](mailto:fowen@brocku.ca)) or the Brock University Research Ethics Officer (905) 688-5550, ext. 3035.

## Appendix D: Consent Form for Interview Participants

**Researchers:** Danielle Fry, CHYS and Dr. Frances Owen, CHYS, Brock University

Name of participant: \_\_\_\_\_

I understand that the purpose of the master's research thesis project in which I have agreed to participate is to examine the experience of community care providers who support individuals with Intellectual Disabilities (ID). In particular, this study seeks to explore the thought processes of care providers as they work through day-to-day ethical decisions and dilemmas.

I understand that my participation includes being interviewed about the processes involved in making ethical decisions about the individual(s) I support. I understand that I will receive a \$10 Tim Horton's gift card as compensation for my time.

I understand that my participation in this study is voluntary and that I may withdraw from the study at any time and for any reason without penalty. If I withdraw from the study at any point, I understand that my audiotaped interview data will be erased, and any written data will be shredded. I understand that that all data will be destroyed by September 1<sup>st</sup>, 2013.

I understand that my decision to participate, or not, will in no way affect my employment or standing within Mainstream.

I understand that, for myself, the risks involved in participating in this study are only minimal (i.e. feeling uncomfortable disclosing some information).

I understand that the interview will be audiotaped and that all of my personal data will be kept strictly confidential. I understand that only the researchers mentioned above will have access to the information I give throughout my participation in the study, my name will not be associated with my comments in this information. Any quotations of the information I share that are used in reporting the results of the study will not be associated with my name. I understand that the researchers will publish articles, and make professional and public presentations using the information that all the people who helped in this study have provided. However, if during the course of my participation in the study I tell you that I, or any person I support in my work with Mainstream, has been abused or will be abused, or is a threat to him/herself or others, the Executive Director will be informed so that this can be reported to the appropriate authorities. I also understand that my personal information will have to be given to the courts if the law requires it.

[ ] Yes, I understand the general nature of this study and my involvement in it. I agree to participate in this study and I understand that I may withdraw at any time without penalty.

[ ] I also give you permission to use my results in other studies that are similar to this one (this is called “secondary analysis”).

[ ] I give permission for you to contact me after the study is over to ask me if I would be willing to answer some more questions or be in a new study.

Participant Signature: \_\_\_\_\_ Date: \_\_\_\_\_

This study has received ethics clearance by the Brock Research Ethics Board (REB - 10-070 - Owen). If I have any questions or concerns about my participation in the study, I may contact Danielle Fry, ([df04ju@brocku.ca](mailto:df04ju@brocku.ca)) or Frances Owen ([fowen@brocku.ca](mailto:fowen@brocku.ca)) or the Brock University Research Ethics Officer (905) 688-5550, 3035.

## Appendix E: Pre-interview Demographic Questionnaire

**\*Note to participants:** All personal information will be kept confidential.

Name: \_\_\_\_\_ Age: \_\_\_\_\_

Email address: \_\_\_\_\_

Mailing address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Phone Number: \_\_\_\_\_

How many individuals do you support at Mainstream? \_\_\_\_\_

*How long have you worked at Mainstream? (please circle one)*

0-1 year      2-5 years      6-9 years      10+ years

*Please circle the program settings in which you work:*

Options Niagara      Resource Centre      Independent Living      24 Hour Support

*Please circle the age ranges(s) of the person(s) you support:*

18-24      25-34      35-44      45-54      55+

This study has received ethics clearance by the Brock Research Ethics Board (REB - 10-070 - Owen).

## Appendix F: Interview Questions

1. Can you describe any previous experience you have working as a care provider for people with ID either in other programs at Mainstream or elsewhere?
2. Please describe your current responsibilities as a care provider.
3. How would you describe the nature of your relationship with the individual(s) you support?
  - a. Please describe the kinds of responsibilities you have toward the person(s) you support.
4. How is this relationship with the person(s) you support at Mainstream, different from other relationships in your life such as your relationship with friends, relatives, co-workers?
5. How often do you participate in making decisions about the individual you support?
6. Please describe a time when you had to decide whether a person you support could make a decision for him/herself.
7. What factors do you consider when deciding whether or not a person can make his or her own decisions?
  - a. What indicators do you use when determining how much help a person needs to make decisions?
  - b. Does the perceived intellectual capacity of the individual you support influence your decision-making? How?
  - c. Does the individual's age influence your ethical decision-making? How?
8. What are the consequences for you in your job if a person you support makes a decision that results in something going wrong?
9. How would you define "good quality of care" regarding the care provided to the individual(s) you support in your job?
10. Please describe the process of providing care/protection for the person you support and also supporting that person to make his/her own decisions/choices?
11. How would you define an "ethical concern" in the context of your job as a care provider?
12. Please describe a time when you felt uncertain about making an ethical decision in the context of your work at Mainstream.

- a. Can you describe what sources of information you used (if any) to help you resolve the ethical concern?
13. If you have questions about an ethical issue regarding the individual you support, who do you go to?
- a. What other sources of information do you seek when faced with a difficult ethical decision?
    - i. How often do you seek these sources of information/support?
14. Have you ever approached your supervisor/manager for advice about an ethical concern?  
If yes:
- a. Can you describe a specific situation in which you approached your manager for advice?
  - b. Can you describe the outcome of this situation in which you sought advice/support?
15. What sources of information do you wish you could use to help in making ethical decisions about the individual(s) you support?
16. How did you learn about ethics/ethical practice?
17. Please describe any training you have received in ethics/ethical practice.
- a. Where did you receive this training?
  - b. When did you participate in this training?
18. Have you had rights training? If so, when?
- a. What training did you participate in?
  - b. Have you participated in the 3Rs: Rights, Respect and Responsibility staff training?
    - i. If so, when?
19. Did the rights training impact your thinking about ethical decision-making? If so, how?
20. Can you describe what it would look like to respect the rights of the person you support in your work setting?
21. When did you last read Mainstream's Code of Ethics?
- a. Do you use the Code of Ethics in your job as a care provider at Mainstream?
  - b. (If yes) Can you describe how you use the Code of Ethics in your work at Mainstream?
22. How are your job responsibilities similar or different compared to the job responsibilities of care providers working in residential (or) day programs?

23. In your experience, how similar or different are the ethical concerns faced by care providers in residential care versus those faced by care providers in day programs?



Appendix G: Table of Research Questions, Interview Questions and Themes

Research Questions	Interview Questions	Corresponding Theme
<p>How do care providers in residential and day program settings describe the ethical decision-making process?</p> <p>Are there differences in the way care providers in residential settings and care providers in non-residential settings describe the ethical decision-making process?</p>	<p>How often do you participate in making decisions about the individual you support?</p> <p>Please describe a time when you felt uncertain about making an ethical decision in the context of your work at Mainstream.</p> <p>How would you define an “ethical concern” in the context of your job as a care provider?</p> <p>In your experience, how similar or different are the ethical concerns faced by care providers in residential care versus those faced by care providers in day programs?</p>	Care Providers’ Descriptions of Ethical Decision-Making
2. How do care providers working with individuals with Intellectual Disabilities describe the balance between duty of care and the right to self-determination of the people they support when it comes to ethical decision-making processes?	<p>Please describe the process of providing care/protection for the person you support and also supporting that person to make his/her own decisions/choices?</p> <p>Please describe a time when you had to decide whether a person you support could make a decision for him/herself.</p> <p>What factors do you consider when deciding whether or not</p>	Balancing Duty of Care and Promotion of Self-Determination

	<p>a person can make his or her own decisions?</p> <p>What indicators do you use when determining how much help a person needs to make decisions?</p> <p>Does the perceived intellectual capacity of the individual you support influence your decision-making? How?</p> <p>Does the individual's age influence your ethical decision-making? How?</p>	
<p>3. What sources of information guide the cognitive processes of ethical decision-making?</p> <p>a) What sources of information do care providers find most helpful in making ethical decisions?</p> <p>b) What sources of information do care providers think would be helpful in navigating ethical decision-making?</p>	<p>If you have questions about an ethical issue regarding the individual you support, who do you go to?</p> <p>What other sources of information do you seek when faced with a difficult ethical decision?</p> <p>How often do you seek these sources of information/support?</p> <p>Have you ever approached your supervisor/manager for advice about an ethical concern?</p> <p>What sources of information do you wish you could use to help in making ethical decisions about the individual(s) you support?</p>	Supervisors and Colleagues as Sources of Information for Ethical Decision-Making

## Appendix H: Canadian Association of Social Workers Code of Ethics - Core Social Work Values and Principles

### **Value 1: Respect for the Inherent Dignity and Worth of Persons**

Social work is founded on a long-standing commitment to respect the inherent dignity and individual worth of all persons. When required by law to override a client's wishes, social workers take care to use the minimum coercion required. Social workers recognize and respect the diversity of Canadian society, taking into account the breadth of differences that exist among individuals, families, groups and communities. Social workers uphold the human rights of individuals and groups as expressed in The Canadian Charter of Rights and Freedoms (1982) and the United Nations Universal Declaration of Human Rights (1948).

#### **Principles:**

- Social workers respect the unique worth and inherent dignity of all people and uphold human rights.
- Social workers uphold each person's right to self-determination, consistent with that person's capacity and with the rights of others.
- Social workers respect the diversity among individuals in Canadian society and the right of individuals to their unique beliefs consistent with the rights of others.
- Social workers respect the client's right to make choices based on voluntary, informed consent.
- Social workers who have children as clients determine the child's ability to consent and where appropriate, explain to the child and to the child's parents/guardians, the nature of the social worker's relationship to the child.
- Social workers uphold the right of society to impose limitations on the self-determination of individuals, when such limitations protect individuals from self-harm and from harming others.
- Social workers uphold the right of every person to be free from violence and threat of violence.

### **Value 2: Pursuit of Social Justice**

Social workers believe in the obligation of people, individually and collectively, to provide resources, services and opportunities for the overall benefit of humanity and to afford them protection from harm. Social workers promote social fairness and the equitable distribution of resources, and act to reduce barriers and expand choice for all persons, with special regard for those who are marginalized, disadvantaged, vulnerable, and/or have exceptional needs. Social workers oppose prejudice and discrimination against any person or group of persons, on any grounds, and specifically challenge views and actions that stereotype particular persons or groups.

#### **Principles:**

- Social workers uphold the right of people to have access to resources to meet basic human needs.
- Social workers advocate for fair and equitable access to public services and benefits.
- Social workers advocate for equal treatment and protection under the law and challenge injustices, especially injustices that affect the vulnerable and disadvantaged.

- Social workers promote social development and environmental management in the interests of all people.

### **Value 3: Service to Humanity**

The social work profession upholds service in the interests of others, consistent with social justice, as a core professional objective. In professional practice, social workers balance individual needs, and rights and freedoms with collective interests in the service of humanity. When acting in a professional capacity, social workers place professional service before personal goals or advantage, and use their power and authority in disciplined and responsible ways that serve society. The social work profession contributes to knowledge and skills that assist in the management of conflicts and the wide-ranging consequences of conflict.

#### **Principles:**

- Social workers place the needs of others above self-interest when acting in a professional capacity.
- Social workers strive to use the power and authority vested in them as professionals in responsible ways that serve the needs of clients and the promotion of social justice.
- Social workers promote individual development and pursuit of individual goals, as well as the development of a just society.
- Social workers use their knowledge and skills in bringing about fair resolutions to conflict and in assisting those affected by conflict.

### **Value 4: Integrity in Professional Practice**

Social workers demonstrate respect for the profession's purpose, values and ethical principles relevant to their field of practice. Social workers maintain a high level of professional conduct by acting honestly and responsibly, and promoting the values of the profession. Social workers strive for impartiality in their professional practice, and refrain from imposing their personal values, views and preferences on clients. It is the responsibility of social workers to establish the tenor of their professional relationship with clients, and others to whom they have a professional duty, and to maintain professional boundaries. As individuals, social workers take care in their actions to not bring the reputation of the profession into disrepute. An essential element of integrity in professional practice is ethical accountability based on this Code of Ethics, the IFSW International Declaration of Ethical Principles of Social Work, and other relevant provincial/territorial standards and guidelines. Where conflicts exist with respect to these sources of ethical guidance, social workers are encouraged to seek advice, including consultation with their regulatory body.

#### **Principles:**

- Social workers demonstrate and promote the qualities of honesty, reliability, impartiality and diligence in their professional practice.
- Social workers demonstrate adherence to the values and ethical principles of the profession and promote respect for the profession's values and principles in organizations where they work or with which they have a professional affiliation.

- Social workers establish appropriate boundaries in relationships with clients and ensure that the relationship serves the needs of clients.
- Social workers value openness and transparency in professional practice and avoid relationships where their integrity or impartiality may be compromised, ensuring that should a conflict of interest be unavoidable, the nature of the conflict is fully disclosed.

**Value 5: Confidentiality in Professional Practice**

A cornerstone of professional social work relationships is confidentiality with respect to all matters associated with professional services to clients. Social workers demonstrate respect for the trust and confidence placed in them by clients, communities and other professionals by protecting the privacy of client information and respecting the client's right to control when or whether this information will be shared with third parties. Social workers only disclose confidential information to other parties (including family members) with the informed consent of clients, clients' legally authorized representatives or when required by law or court order. The general expectation that social workers will keep information confidential does not apply when disclosure is necessary to prevent serious, foreseeable and imminent harm to a client or others. In all instances, social workers disclose the least amount of confidential information necessary to achieve the desired purpose.

**Principles:**

- Social workers respect the importance of the trust and confidence placed in the professional relationship by clients and members of the public.
- Social workers respect the client's right to confidentiality of information shared in a professional context.
- Social workers only disclose confidential information with the informed consent of the client or permission of client's legal representative.
- Social workers may break confidentiality and communicate client information without permission when required or permitted by relevant laws, court order or this *Code*.
- Social workers demonstrate transparency with respect to limits to confidentiality that apply to their professional practice by clearly communicating these limitations to clients early in their relationship.

**Value 6: Competence in Professional Practice**

Social workers respect a client's right to competent social worker services. Social workers analyze the nature of social needs and problems, and encourage innovative, effective strategies and techniques to meet both new and existing needs and, where possible, contribute to the knowledge base of the profession. Social workers have a responsibility to maintain professional proficiency, to continually strive to increase their professional knowledge and skills, and to apply new knowledge in practice commensurate with their level of professional education, skill and competency, seeking consultation and supervision as appropriate.

**Principles:**

- Social workers uphold the right of clients to be offered the highest quality service possible.
- Social workers strive to maintain and increase their professional knowledge and skill.

- Social workers demonstrate due care for client's interests and safety by limiting professional practice to areas of demonstrated competence.
- Social workers contribute to the ongoing development of the profession and its ability to serve humanity, where possible, by participating in the development of current and future social workers and the development of new professional knowledge.
- Social workers who engage in research minimize risks to participants, ensure informed consent, maintain confidentiality and accurately report the results of their studies.

Retrieved from: <http://www.casw-acts.ca/>

## Appendix I: Values and Principles of the Code of Ethics of the National Association of Social Worker

### Value: *Service*

*Ethical Principle: Social workers' primary goal is to help people in need and to address social problems.*

Social workers elevate service to others above self-interest. Social workers draw on their knowledge, values, and skills to help people in need and to address social problems. Social workers are encouraged to volunteer some portion of their professional skills with no expectation of significant financial return (pro bono service).

### Value: *Social Justice*

*Ethical Principle: Social workers challenge social injustice.*

Social workers pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people. Social workers' social change efforts are focused primarily on issues of poverty, unemployment, discrimination, and other forms of social injustice. These activities seek to promote sensitivity to and knowledge about oppression and cultural and ethnic diversity. Social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people.

### Value: *Dignity and Worth of the Person*

*Ethical Principle: Social workers respect the inherent dignity and worth of the person.*

Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients' socially responsible self-determination. Social workers seek to enhance clients' capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society. They seek to resolve conflicts between clients' interests and the broader society's interests in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession.

### Value: *Importance of Human Relationships*

*Ethical Principle: Social workers recognize the central importance of human relationships.*

Social workers understand that relationships between and among people are an important vehicle for change. Social workers engage people as partners in the helping process. Social workers seek to strengthen relationships among people in a purposeful effort to promote, restore, maintain, and enhance the wellbeing of individuals, families, social groups, organizations, and communities.

Value: *Integrity*

Ethical Principle: *Social workers behave in a trustworthy manner.*

Social workers are continually aware of the profession's mission, values, ethical principles, and ethical standards and practice in a manner consistent with them. Social workers act honestly and responsibly and promote ethical practices on the part of the organizations with which they are affiliated.

Value: *Competence*

Ethical Principle: *Social workers practice within their areas of competence and develop and enhance their professional expertise.*

Social workers continually strive to increase their professional knowledge and skills and to apply them in practice. Social workers should aspire to contribute to the knowledge base of the profession.

Retrieved from: <http://www.socialworkers.org/pubs/code/code.asp>



Appendix J: Overview of Principles outlined in Canadian Code of Ethics for Psychologists

**Principle I: Respect for the Dignity of Persons.** This principle, with its emphasis on moral rights, generally should be given the highest weight, except in circumstances in which there is a clear and imminent danger to the physical safety of any person.

**Principle II: Responsible Caring.** This principle generally should be given the second highest weight. Responsible caring requires competence and should be carried out only in ways that respect the dignity of persons.

**Principle III: Integrity in Relationships.** This principle generally should be given the third highest weight. Psychologists are expected to demonstrate the highest integrity in all of their relationships. However, in rare circumstances, values such as openness and straightforwardness might need to be subordinated to the values contained in the Principles of Respect for the Dignity of Persons and Responsible Caring.

**Principle IV: Responsibility to Society.** This principle generally should be given the lowest weight of the four principles when it conflicts with one or more of them. Although it is necessary and important to consider responsibility to society in every ethical decision, adherence to this principle must be subject to and guided by Respect for the Dignity of Persons, Responsible Caring, and Integrity in Relationships. When a person's welfare appears to conflict with benefits to society, it is often possible to find ways of working for the benefit of society that do not violate respect and responsible caring for the person. However, if this is not possible, the dignity and well-being of a person should not be sacrificed to a vision of the greater good of society, and greater weight must be given to respect and responsible caring for the person.

Retrieved from:

<http://www.cpa.ca/cpasite/userfiles/Documents/Canadian%20Code%20of%20Ethics%20for%20Psycho.pdf>

## Appendix K: Overview of Ethical Principles of Psychologists and Code of Conduct (APA)

### **Principle A: Beneficence and Nonmaleficence**

Psychologists strive to benefit those with whom they work and take care to do no harm. In their professional actions, psychologists seek to safeguard the welfare and rights of those with whom they interact professionally and other affected persons, and the welfare of animal subjects of research. When conflicts occur among psychologists' obligations or concerns, they attempt to resolve these conflicts in a responsible fashion that avoids or minimizes harm. Because psychologists' scientific and professional judgments and actions may affect the lives of others, they are alert to and guard against personal, financial, social, organizational, or political factors that might lead to misuse of their influence. Psychologists strive to be aware of the possible effect of their own physical and mental health on their ability to help those with whom they work.

### **Principle B: Fidelity and Responsibility**

Psychologists establish relationships of trust with those with whom they work. They are aware of their professional and scientific responsibilities to society and to the specific communities in which they work. Psychologists uphold professional standards of conduct, clarify their professional roles and obligations, accept appropriate responsibility for their behavior, and seek to manage conflicts of interest that could lead to exploitation or harm. Psychologists consult with, refer to, or cooperate with other professionals and institutions to the extent needed to serve the best interests of those with whom they work. They are concerned about the ethical compliance of their colleagues' scientific and professional conduct. Psychologists strive to contribute a portion of their professional time for little or no compensation or personal advantage.

### **Principle C: Integrity**

Psychologists seek to promote accuracy, honesty, and truthfulness in the science, teaching, and practice of psychology. In these activities psychologists do not steal, cheat, or engage in fraud, subterfuge, or intentional misrepresentation of fact. Psychologists strive to keep their promises and to avoid unwise or unclear commitments. In situations in which deception may be ethically justifiable to maximize benefits and minimize harm, psychologists have a serious obligation to consider the need for, the possible consequences of, and their responsibility to correct any resulting mistrust or other harmful effects that arise from the use of such techniques.

### **Principle D: Justice**

Psychologists recognize that fairness and justice entitle all persons to access to and benefit from the contributions of psychology and to equal quality in the processes, procedures, and services being conducted by psychologists. Psychologists exercise reasonable judgment and take precautions to ensure that their potential biases, the boundaries of their competence, and the limitations of their expertise do not lead to or condone unjust practices.

### **Principle E: Respect for People's Rights and Dignity**

Psychologists respect the dignity and worth of all people, and the rights of individuals to privacy,

confidentiality, and self-determination. Psychologists are aware that special safeguards may be necessary to protect the rights and welfare of persons or communities whose vulnerabilities impair autonomous decision making. Psychologists are aware of and respect cultural, individual, and role differences, including those based on age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, language, and socioeconomic status and consider these factors when working with members of such groups. Psychologists try to eliminate the effect on their work of biases based on those factors, and they do not knowingly participate in or condone activities of others based upon such prejudices.

Retrieved from: <http://www.apa.org/ethics/code/index.aspx>

## Appendix L: National Alliance of Direct Support Professionals Code of Ethics

### 1. Person-Centered Supports

As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.

As a DSP, I will -

- Recognize that each person must direct his or her own life and support and that the unique social network, circumstances, personality, preferences, needs and gifts of each person I support must be the primary for guide the selection, structure, and use of supports for that individual.
- Commit to person-centered supports as best practice.
- Provide advocacy when the needs of the system override those of the individual(s) I support, or when individual preferences, needs or gifts are neglected for other reasons.
- Honor the personality, preferences, culture and gifts of people who cannot speak by seeking other ways of understanding them.
- Focus first on the person, and understand that my role in direct supports will require flexibility, creativity and commitment.

### 2. Promoting Physical and Emotional Well-Being

As a DSP, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.

As a DSP, I will -

- Develop a relationship with the people I support that is respectful, based on mutual trust, and that maintains professional boundaries.
- Assist the individuals I support to understand their options and the possible consequences of these options as they relate to their physical health and emotional well-being.
- Promote and protect the health, safety, and emotional well-being of an individual by assisting the person in preventing illness and avoiding unsafe activity. I will work with the individual and his or her support network to identify areas of risk and to create safeguards specific to these concerns.
- Know and respect the values of the people I support and facilitate their expression of choices related to those values.
- Challenge others, including support team members (e.g. doctors, nurses, therapists, co-workers, family members) to recognize and support the rights of individuals to make informed decisions even when these decisions involve personal risk.
- Be vigilant in identifying, discussing with others, and reporting any situation in which the individuals I support are at risk of abuse, neglect, exploitation or harm.
- Consistently address challenging behaviors proactively, respectfully, and by avoiding the use of aversive or deprivation intervention techniques. If these techniques are included in an approved support plan I will work diligently to find alternatives and will advocate for the eventual elimination of these techniques from the person's plan.

### 3. Integrity and Responsibility

As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.

As a DSP, I will -

- Be conscious of my own values and how they influence my professional decisions.
- Maintain competency in my profession through learning and ongoing communication with others.
- Assume responsibility and accountability for my decisions and actions.
- Actively seek advice and guidance on ethical issues from others as needed when making decisions.
- Recognize the importance of modeling valued behaviors to co-workers, persons receiving support, and the community at-large.
- Practice responsible work habits.

### 4. Confidentiality

As a DSP, I will safeguard and respect the confidentiality and privacy of the people I support.

As a DSP, I will -

- Seek information directly from those I support regarding their wishes in how, when and with whom privileged information should be shared.
- Seek out a qualified individual who can help me clarify situations where the correct course of action is not clear.
- Recognize that confidentiality agreements with individuals are subject to state and agency regulations.
- Recognize that confidentiality agreements with individuals should be broken if there is imminent harm to others or to the person I support.

### 5. Justice, Fairness and Equity

As a DSP, I will promote and practice justice, fairness, and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights and responsibilities of the people I support.

As a DSP, I will -

- Help the people I support use the opportunities and the resources of the community available to everyone.
- Help the individuals I support understand and express their rights and responsibilities.
- Understand the guardianship or other legal representation of individuals I support, and work in partnership with legal representatives to assure that the individual's preferences and interests are honored.

### 6. Respect

As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.

As a DSP, I will -

- Seek to understand the individuals I support today in the context of their personal history, their social and family networks, and their hopes and dreams for the future.
- Honor the choices and preferences of the people I support.
- Protect the privacy of the people I support.
- Uphold the human rights of the people I support.
- Interact with the people I support in a respectful manner.
- Recognize and respect the cultural context (e.g. religion, sexual orientation, ethnicity, socio-economic class) of the person supported and his/her social network.
- Provide opportunities and supports that help the individuals I support be viewed with respect and as integral members of their communities.

## **7. Relationships**

As a DSP, I will assist the people I support to develop and maintain relationships.

As a DSP, I will -

- Advocate for the people I support when they do not have access to opportunities and education to facilitate building and maintaining relationships.
- Assure that people have the opportunity to make informed choices in safely expressing their sexuality.
- Recognize the importance of relationships and proactively facilitate relationships between the people I support, their family and friends.
- Separate my own personal beliefs and expectations regarding relationships (including sexual relationships) from those desired by the people I support based on their personal preferences. If I am unable to separate my own beliefs/preferences in a given situation, I will actively remove myself from the situation.
- Refrain from expressing negative views, harsh judgments, and stereotyping of people close to the individuals I support.

## **8. Self-Determination**

As a DSP, I will assist the people I support to direct the course of their own lives.

As a DSP, I will -

- Work in partnership with others to support individuals leading self-directed lives.
- Honor the individual's right to assume risk in an informed manner.
- Recognize that each individual has potential for lifelong learning and growth.

## **9. Advocacy**

As a DSP, I will advocate with the people I support for justice, inclusion, and full community participation.

As a DSP, I will -

- Support individuals to speak for themselves in all matters where my assistance is needed.
- Represent the best interests of people who cannot speak for themselves by finding alternative ways of understanding their needs, including gathering information from others who represent their best interests.
- Advocate for laws, policies, and supports that promote justice and inclusion for people with disabilities and other groups who have been disempowered.

- Promote human, legal, and civil rights of all people and assist others to understand these rights.
- Recognize that those who victimize people with disabilities either criminally or civilly must be held accountable for their actions.
- Find additional advocacy services when those that I provide are not sufficient.
- Consult with people I trust when I am unsure of the appropriate course of action in my advocacy efforts.

Retrieved from: <http://www.nadsp.org/docs/CodeofEthicsPrintout.pdf>